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Caregiving relationships in families of Children with Psychotic-Like Experiences

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Volume I
Main Research Project

Claire Tobin

Submitted in partial fulfilment of the
Doctorate in Clinical Psychology,
Institute of Psychiatry,
King's College London.

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Overview

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Caregiving Relationships in Families of Children with Psychotic-like Experiences.

Supervised by Drs Suzanne Jolley, Juliana Onwumere & Prof Elizabeth Kuipers

Abstract

AIMS: Caring for a child with emotional and/or behavioural problems can cause considerable stress for parents, which can in turn impact adversely on parent-child relationships. A difficult family environment increases the risk of negative outcomes for both children and their parents, and plays a key role in the evolution and recurrence of psychotic symptoms. This study will examine the applicability of a cognitive model of caregiving to a group of parents of clinically referred children, and associations between the family environment and severity of Psychotic-Like Experiences (PLEs). **METHOD:** Parents (or those *in loco parentis*; $n=44$) of clinically referred children were interviewed using standardised measures, to examine their coping strategies, threat appraisals, mood, social support, child difficulties and levels of expressed emotion (EE). Children were also asked to self-report their difficulties (PLEQ and SDQ). **RESULTS:** Parents reported high levels of depression and anxiety, which were predicted by their threat appraisals about their children's problems, and were associated with less adaptive coping, less social support, and more threatening appraisals. Parent mood predicted EE in the parent-child relationship, and was significantly correlated with higher reports of child emotional and behavioural difficulties. Child-reported difficulties were not associated with parent factors. **CONCLUSION:** Findings support the application of the cognitive model of caregiving to parents of clinically referred children, and suggest novel parent-focused interventions to reduce caregiver distress. Such interventions would also have the potential to reduce the future risk of mental health problems for both children and their parents.

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Overview

Intervening early in childhood to prevent future risk of mental health problems is economically effective and is part of the current governmental strategy (Department of Health, 2011*a, b*; McCrone, Dhanisiri, Patel, Knapp & Lawton-Smith, 2008). Childhood interventions need to include both parent and child-focused work, as parent and child outcomes are inter-dependent. Psychotic-like experiences (PLEs) include altered perceptions such as hearing or seeing things that others cannot, magical thinking and having ideas that may appear odd to others. They are common (up to two thirds of young people report them) and often transient and unproblematic. However, when PLEs are persistent and distressing, they may represent a risk factor for the later development of mental health problems, including psychosis, one of the most costly mental health conditions. Distressing PLEs are also considered to be a target for intervention in their own right, with both individual and family cognitive behavioural interventions recommended (National Institute for Health and Care Excellence [NICE], 2012). At present, the recommendation is based on research in adults with psychosis, and the assumption that similar psychological processes underlie PLE severity, distress and persistence as contribute to the development and maintenance of psychosis. Emerging research indicates that this assumption has some justification, both at the level of the individual, and the family environment. Specifically, familial expressed emotion (EE) has been found to be associated with PLEs in childhood in one population study, and with PLEs in the at-risk mental state in adolescence.

While this is promising, a great deal of further work is needed to understand the psychological processes contributing to the development of problematic PLEs, and the mechanisms by which they increase future mental health risk. This understanding will then contribute to the refinement of the recommended adult interventions to suit children and their families, in order to maximise their effectiveness in alleviating current distress, with the potential to also reduce future risk.

In particular, a better understanding of the needs of caregivers and other family members is required. Cognitive behavioural family interventions target cognitive, emotional and behavioural processes in caregivers in order to improve the caregiving relationship. Key factors are caregiver emotional problems (depression and anxiety), caregiver appraisals of the problem and how it is managed, caregiver coping strategies, and their support networks. Significant differences in these factors would be expected in families of adults with psychosis, compared to families of children presenting with emotional and behavioural difficulties, irrespective of their association with distressing PLEs. Those who already hold parental responsibility, for example, may only require an adaptation to their existing caregiver role, in

the context of a child's emotional and behavioural difficulties. Many caregiver appraisals and behaviours that may be unhelpful when dealing with an adult child with psychosis, may impact differently in childhood. On the other hand, the parental role carries significant stress itself, and the additional burden of the child's emotional and behavioural problems may be less readily accommodated. It is unclear therefore, what adaptations to the cognitive behavioural family interventions recommended in the NICE guidance would be required for this group. Further investigation is needed into the psychological processes comprising the key targets of cognitive behavioural family interventions, in the context of childhood difficulties in general, as well as the potential interaction between these factors and the severity of childhood PLEs.

This thesis is an investigation of the applicability of a cognitive model of caregiving to parents of clinically referred children, and of the association between family environment and the severity of childhood PLEs. A number of factors have been found to influence the impact of caregiving on caregivers of adults, in particular those with psychosis (Kuipers, Onwumere & Bebbington, 2010), but less is known about these factors in the carers of children with emotional and behavioural disorders, who are usually parents. Understanding the nature of parent factors and caregiving relationships for children with emotional and behavioural difficulties referred to community mental health services can help to provide better support to families, and has the potential to reduce the risk of mental health problems for both children and their parents.

The aims of the study are twofold. The first aim is to identify the processes underlying parental distress and high expressed emotion in this group of young people, in order to inform cognitive behavioural interventions to support caregivers, and thereby improve outcomes for both parent and child.

The second aim is to investigate the association between parental difficulties and childhood problems, both overall, and specifically in relation to the severity of PLEs.

In the literature review, I shall first review common mental health presentations in children, before moving on to discuss PLEs more specifically. I will outline current PLE prevalence estimates, and their prognostic significance. I will go on to review parent difficulties associated with caring for a child with emotional and behavioural problems. Subsequently, the association between parent and child difficulties will be considered, including the role of the parent-child relationship. The role of EE in influencing both child and parent outcomes will be specifically addressed. I will conclude by considering a cognitive model of caregiving, and how the various components of this model may apply to parents of children with PLEs, emotional and behavioural difficulties, and the parent-child relationship.

Chapters Two and Three will describe the methodology of the study and the results obtained, and in the final chapter, I will summarise the findings, consider the limitations of the current study, and, notwithstanding these, the implications for future research and clinical practice. I will conclude by recommending that CAMHS services also focus on parental need, providing interventions based on cognitive models of caregiving. The recommendation is in line with current governmental policies, and such interventions carry the promise of improving current and future clinical outcomes for both parents and young people.

Introduction

Childhood Mental Health Problems

Mental health problems are common in children and adolescents (henceforth referred to as 'children'). It is estimated that one in five children have a mental health problem in any given year, and one in ten children have a mental health problem at any one time in the UK (St John, Leon & McCulloch, 2005). In the United Kingdom, children who display signs of mental health difficulties can be referred to the Child and Adolescent Mental Health Services (CAMHS) by a relevant professional such as their GP, teacher or social worker. Mental health problems in children are defined as abnormalities of emotion, behaviour or social relationships, sufficiently marked or prolonged to cause suffering or risk to optimal development in the child or distress or disturbance in the family or community (Denver, Pelly & Thornton, 1999). This definition emphasises the need to consider parents in their role as caregivers.

Mental health problems in children include a variety of internalizing problems (e.g. anxiety and depression) and externalizing problems (e.g. conduct problems or attention difficulties). Prevalence data for mental health problems in British children is outlined in Table 1 (Green, McGinnity, Meltzer, Ford & Goodman, 2005). Anxiety disorders are the most common of the emotional disorders reported; these include separation anxiety, generalized anxiety, specific phobias, social phobias, panic, agoraphobia, post-traumatic stress, and obsessive-compulsive disorder. The prevalence of depression includes children with depressive episodes, as well as those with depression meeting full diagnostic criteria. Conduct disorders include oppositional defiant disorder and unsocialised and socialised conduct disorder. Other less common disorders include autistic spectrum disorder, tic disorders, mutism, eating disorder and psychosis (Green *et al.*, 2005).

With prevalence rates of one in ten, it is clear that many children with mental health difficulties do not present to CAMHS. Green *et al.* (2005) reported that only 28.0% of parents of children with conduct disorder had sought advice from a mental health specialist in the previous year. Similarly, just under a quarter of children with an emotional disorder had contacted, or been referred to, a mental health service in the previous year. Adults who seek help from mental health services differ from children seeking help, because children rarely refer themselves for treatment. The presence of a problem is therefore not sufficient to explain help-seeking for children. Research has found that parents' levels of perceived burden are a major reason for mental health service use for children (Angold, Messer, Stangl, Farmer, Costello & Burns, 1998). Child symptomatology and parents' own mental health problems predicted parents' perceived burden. The effects of childhood disorder severity on mental health service use were mediated by the level of parent burden (Angold *et al.*, 1998).

Table 1: Point Prevalence of Child Emotional and Mental Health Disorders (5- 16 years)
adapted from Green, McGinnity, Meltzer, Ford & Goodman (2005)

Disorder	Percentage
Any Disorder	9.6
Emotional Disorders	3.7
Anxiety disorders	3.3
Depression	0.9
Conduct Disorders	5.8
Hyperkinetic disorder	1.8
Other less common disorders	1.3

Psychotic-like experiences

Hearing or seeing things that others cannot, magical thinking, or having ideas that may appear odd to others, is a relatively common phenomenon. Van Os *et al.* (2009) have proposed a dimensional view of PLEs, whereby the frequency of PLEs is distributed in the general population along a continuum of severity. A meta-analysis found the median PLE prevalence in the general population was 8.4 % (Inter Quartile Range: 3.5–20.9%; van Os *et al.*, 2009), with higher rates obtained using self-report questionnaires (up to 40%) compared to clinical interview. An updated meta-analysis of PLEs in children and adults found a prevalence rate of 7.2% (Linscott, & Van Os, 2012). Prevalence rates reported for children and adolescents tend to be higher than for adults (6-66%; Dhossche, Ferdinand, van der Ende, Hofstra & Verhulst, 2002; Laurens, Hodgins, Taylor & Murray, 2011; McGorry *et al.*, 1995; Yoshizumi, Murase, Honjo, Kaneko & Murakami, 2004).

PLEs are usually transient, and do not necessarily cause difficulties (Laurens *et al.*, 2011). For most individuals PLEs reduce or remit over time (Hanssen, Bak, Bijl, Vollebergh & van Os, 2005). Results of community surveys show that the majority of children reporting PLEs were not distressed by them (Laurens *et al.*, 2007; 2011). However, PLEs have been associated with a range of other difficulties; in a community sample ($n=258$) Laurens and colleagues (2007) found that 17.4% of children aged 9-15 with self-reported PLEs also had social, emotional or behavioural difficulties (scores in the top of the 10th percentile on the Strengths and Difficulties Questionnaire [SDQ]; Goodman *et al.*, 2000). In a larger community sample ($n= 1347$) 14.8% of children who reported a 'certain experience' of at least one PLE also scored in the 'abnormal'

range on the SDQ, and a third of children experienced both distress and functional impairment specifically related to their PLEs (Laurens *et al.*, 2011). Furthermore, a birth cohort study found that young people with psychotic symptoms reported a higher level of depression and anxiety than control participants (Polanczyk *et al.*, 2010). The authors also describe an intermediate group, possibly akin to a PLE group, who had higher levels of depression and anxiety than control children, but less than the children with psychotic symptoms. Longitudinal research has also identified PLEs as a possible risk factor for the future development of mental health problems for a subset of adolescents (Hanssen *et al.*, 2005; Poulton *et al.*, 2000; van Os, Linscott, Myin-Germeys, Delespaul & Krabbendam, 2009; Welham *et al.*, 2009).

Yung *et al.* (2006) found that PLEs were common in non-psychotic help-seekers aged 15-24 years. Almost their entire sample (98.6%, $n=138$) reported experiencing a PLE at least “sometimes” in their lifetime. Those reporting distress associated with their PLEs were at higher risk for poorer mental health outcomes. Analyses produced a three factor solution for PLEs: ‘Bizarre Experiences’ (e.g. hearing voices, seeing things), ‘Persecutory Ideas’ (e.g. being spied upon or controlled) and ‘Magical Thinking’ (e.g. telepathic communication, having special powers or being sent special messages). The presence of ‘Persecutory Ideas’ and ‘Bizarre Experiences’ were more likely to be associated with distress, depression and poorer functioning than ‘Magical Thinking’. The authors concluded that ‘Bizarre Experiences’ and ‘Persecutory Ideas’ might confer heightened risk for the development of serious mental illness.

PLE Associated Difficulties

PLEs are predictive of poorer outcomes for young people when they are associated with functional, emotional and behavioural difficulties (Yung *et al.*, 2006). Population-based studies with younger samples also indicate that PLEs are associated with an increased risk of a variety of psychological disorders, but future risk is not necessarily related to psychosis. Kelleher and colleagues (2012) found that PLEs increased in a dose-response fashion with several internalizing and externalizing disorders, and were increasingly associated with diagnosable psychopathology with age. Poulton and colleagues (2000) found that psychotic symptoms reported at age 11 years preceded both schizophreniform and anxiety disorders at age 26 years, although not mania and depression. Fisher *et al.* (2013), in a longer term follow-up of the Dunedin sample reported in Poulton *et al.* (2000), found similar results for children with ‘strong’ PLEs. These children were at greater risk of developing a range of mental health problems in adulthood, however the increased risk was not specific to a diagnosis of schizophrenia, and the results should be interpreted with caution given the limited sample size ($n=13$). For those young people with PLEs that do convert to a psychotic disorder, the divergence in the developmental trajectories is more pronounced over time; differences in

attention, emotional, social and behavioral problems increase with age (Yung *et al.*, 2003). Research on a sample of children at-risk for psychosis (mean age 14.5 years) did not find that parent-reported emotional and behavioural difficulties related to later conversion to psychotic disorder (Simeonova, Attalla, Trotman, Esterberg & Walker, 2011). However, decreased levels of adolescent functioning were associated with conversion to psychosis among older adolescents with prodromal symptoms (mean age 19.1 years; Yung *et al.*, 2003).

Because specificity between childhood PLEs and later onset of schizophrenia or other psychotic disorder is low, concerns were raised about the proposal to include a category of 'Attenuated psychotic symptoms syndrome' in DSM-5, and how that might manifest or affect treatment within child and adolescent psychiatry (*cf.* Arango, 2011). For example, half of cases of childhood depression involve PLEs, particularly auditory hallucinations (Freeman, Poznanski, Grossman, Buchsbaum & Banegas, 1985). Given the relatively low positive predictive value, and the high potential for identifying false-positive cases, the DSM working committee decided against the inclusion of the syndrome in DSM-5 (Maxmen, 2012). The syndrome has been included in the DSM-V appendix for further research (APA, 2013)

The association between PLEs and other emotional and behavioural disorders may be explained by shared risk factors, genetic influences and neurodevelopmental differences (Bartels-Velthuis, van de Willige, Jenner, Van Os & Wiersma, 2011). Alemany and colleagues (2011) found an association between a particular genetic polymorphism and trauma in childhood as a risk factor for PLEs in adults. Neurobiological findings using imaging techniques have also found that similar brain regions are affected in mood disorders and adolescents PLEs (Jacobson *et al.*, 2010).

Although specificity to psychosis is low, PLEs remain a relevant clinical entity in childhood mental health. Bartels-Velthuis and colleagues (2011) found that in PLEs in children become increasingly associated with parent-rated measures of behavioural and emotional problems with the increasing age of the child. Such adjunctive use of observer-report measures may avoid some of the drawbacks of using child self-report measures, cognitive deficits or concerns over stigma and other consequences of endorsing symptoms. Parents are also likely to observe their child in a variety of contexts.

This may indicate that PLEs fall within the normal spectrum of experiences in childhood, but might be expected to discontinue over the course of development. A minority of children will experience distress and impairment associated with PLEs however, and this is associated with an increased likelihood of the future development of mental health problems, including an at-risk mental state (Kelleher & Cannon, 2011; Kelleher *et al.*, 2012). Consequently, Kelleher and colleagues (2012) have suggested that PLEs should be carefully assessed in CAMHS settings.

Their presence may indicate that a child is at risk for emotional and behavioural problems that require a more comprehensive care plan.

PLE Interventions

Guidelines produced by the National Institute for Health and Care Excellence (NICE; 2012) identify PLEs as a target for psychological interventions, where they are associated with distress. The guidelines propose that when children present with transient or attenuated psychotic symptoms that are not sufficient for a diagnosis of psychosis or schizophrenia, consideration should be given to offering the NICE recommended psychological therapies (individual and family cognitive behavioural interventions) and recognised treatments for associated distress (e.g. CBT for anxiety and depression). The inclusion of family targeted interventions is aligned with the systemic approach of CAMHS.

Child and Adolescent Mental Health Service Settings

For many children, emotional and behavioural difficulties, in the presence or absence of PLEs, may not reach the threshold for a diagnosable disorder. These children may be seen by a mental health specialist within Community CAMHS. Community CAMHS services aim to support children with less complex needs who would benefit from brief interventions. Assessments and interventions aim to formulate and treat the child within the context of their family system, emphasising the importance of parents or other primary caregivers when considering childhood emotional and behavioural difficulties. The influence of family factors has been seen as multifaceted; for example, children may be referred to services because a parent's own emotional difficulties make it increasingly challenging for them to manage their child's behaviour. Alternatively the impact of the child's mental health difficulties may have adverse consequences for the parent's emotional well-being.

Children with PLEs which are causing distress or having an impact on their life are likely to present to services. Recent research suggests that up to 80% of community CAMHS referrals have experienced PLEs (Ames *et al.*, submitted). However, because PLEs are not universally associated with distress or negative impact, this group of children represent an important opportunity to research the psychological mechanisms determining the extent to which PLEs are associated with distress and impairment. Understanding the connection between parents' well-being, the parent-child relationship and PLE impact and distress in children may aid the identification of useful treatment targets. Equally, developing an understanding of the parental factors that may protect a child from developing distress related to their PLE may indicate targets for preventative intervention at a parental level.

Parental Well-being

The impact of caring for adult children with psychological disorders, especially schizophrenia spectrum disorders, is relatively well studied (Kuipers *et al.*, 2010); however there is a scarcity of literature on the impact of caregiving of minor-aged children with emotional and behavioural problems (Goldberg-Arnold, Fristad & Gavazzi, 1999). Caring for an adult relative with mental health problems is often an unexpected event in a family; however parents do expect to have caregiving responsibilities for their young children. The additional care associated with a child's mental health problems may be readily accepted and managed by parents as a natural extension of their role. Alternatively, the additional care required may be added to the other emotional and financial strains of parenting, and therefore have a greater impact on parents of children and young adolescents with mental health difficulties (Angold, *et al.*, 1998).

Parental Stress

Parents of children with emotional and behavioural problems report significant parental stress and strain (Taylor-Richardson, Heflinger, & Brown, 2006). Deater-Deckard (2004, p.6) defines parenting stress as,

"A set of processes that lead to aversive psychological and physiological reactions arising from attempts to adapt to the demands of parenthood. This is often experienced as negative feelings and beliefs toward and about the self and the child. By definition, these negative feelings arise directly from the parenting role".

Caregiver strain refers to both the objective, observable impact of caring (e.g. dealing with school problems, increased clinic appointments etc.), as well as the subjective (e.g. increased levels of depression and anxiety) and financial impact of caring (e.g. restricted employment opportunities; Vaughan, Feinn, Bernard, Brereton & Kaufman, 2012). Brannan, Heflinger and Bickman (1997) propose that the impact of caring for a child with mental health problems is often more subjective than objective. This is in line with the cognitive model of stress and coping (Lazarus & Folkman, 1984).

The Cognitive Model of Stress and Coping (Lazarus & Folkman, 1984) provides a framework for understanding how parents may attempt to cope with the stress of having a child with a mental health problem. According to this theory, the stresses of caring are affected by cognitive appraisals of the difficulties of the demands, alongside the available coping resources. The impact of the child's difficulties on the parent (the stressor) will be mediated by the parent's appraisal of the problem, (i.e. their evaluation of the controllability of the child's problems and of their own coping resources, including social support), and secondly by the

actual coping strategies used by the parent. The potential association between parents' emotional well-being, social support, appraisals and coping strategies is further considered in the current research.

Parental Mood Disturbance

Parents who report higher stress and strain are more likely to experience their own mood problems (Brannan & Heflinger, 2001). Some studies have conceptualised caregiver strain as a risk factor for mood problems, while others have seen mood disturbance as an explanatory variable contributing to caregiver strain (i.e. depressed parents interpret their caregiving role as burdensome; Brannan & Heflinger, 2001).

Informal caregivers report higher rates of affective and anxiety disorders than non-caregivers, independently of the age of the care recipient (Cochrane, Goering & Rodgers, 1997). A review of 44 studies showed high levels of parental distress in families of children with mental health problems (Early & Poertner, 1993). More than 79.0% of parents of children with an externalising disorder (conduct disorder), aged eight or above, reported clinically significant levels of depression (Hutchings *et al.*, 2011). Similarly, parents of children with internalising disorders also report poorer overall mental health and higher levels of depression, compared with controls (Tan & Rey, 2005). In a community sample, Green *et al.* (2005) found that half of the parents of children with conduct and emotional disorders reported scores indicative of an emotional disorder for themselves.

The severity of childhood depression is positively associated with the level of depression, anxiety, social and somatic symptoms reported by mothers (Wilkinson, Harris, Kelvin, Dubicka & Goodyer, 2012). Recent evidence that found that mothers of children referred to mental health services for internalising and externalising difficulties produced a greater number of worries and a higher catastrophic content than mothers of non-referred children (Triantafyllou, Cartwright-Hatton, Korpa, Kolaitis & Barrowclough, 2012).

Relationship Between Child and Parent Factors

The mechanism by which parent mood problems are related to child mental health problems is unclear. Intergenerational transmission of mental health problems is only partially mediated by genetics; environmental pathways have also been proposed (Goodman & Gotlib, 1999). Evidence suggests that if maternal mood problems are treated then the child's symptoms also remit (Gunlicks & Weisman, 2008; Weissman *et al.*, 2006). Similar results have been found for externalising disorder, whereby improvement in maternal depression was found to be a significant mediator of improvement in child behaviour (Hutchings, Bywater, Williams & Lane, 2012). Parental emotional well-being has thus been viewed a risk factor for mental health

problems in the child. Goodman and Gotlib (1999) argue that, as depression in parents is related to maladaptive cognitions, children may adopt these maladaptive cognitions through social learning or modelling; and this may increase the risk of the child developing depression. Studies supporting this hypothesis have shown that mothers with anxiety problems and mothers of children with anxiety problems tend to catastrophize and expect negative outcomes when conversing with their children (Moore, Whaley & Sigman, 2004; Whaley, Pinto & Sigman, 1999).

Elsewhere in the literature, however, children's symptomatology has been considered as a risk factor for poorer parental emotional well-being (Wilkinson *et al.*, 2012). Parental strain has been found to mediate the relationship between parent and child mental health outcomes (Sales, Greeno, Shear, Anderson, 2004). Beardslee, Gladstone & O'Connor (2011) suggest that the impact of risk factors between child and parent mental health problems is bidirectional: parental behaviours influence child outcome, and child behaviours influence the parental outcome. In all explanatory models, the need to consider both parent and child factors when treating children with mental health problems in clinical settings is emphasised.

Although, children of parents with affective disorders are at increased risk for internalizing disorders and other difficulties, and parents of children with emotional and behavioural problems are at increased risk for parental strain and poorer well-being, many families do manage to cope with these problems however. This may be due to factors such as parental social support, personal coping strategies and parent appraisals. These parent factors, and the child's emotional and behavioural problems, may impact on the parent-child relationship. The strain of caring for a child with mental health problems may interfere with the quality of a parent's relationship with their child. This may put the child at risk for the development of further symptoms, and/or worsen current symptoms. Poor relationships could also increase the negative impact of care on the parent, including an increased risk for poorer emotional well-being. Previous studies have suggested that aspects of the parent-child relationship, such as high levels of criticism, may mediate the association between parent and child difficulties (Bolton *et al.*, 2003). The relationship between parent affective disorders and the severity of child PLEs will be examined in the current study. In addition, dyadic outcomes within the parent-child relationship will be considered, specifically the presence of EE, a well-known measure of the family environment.

Expressed Emotion

Beardslee, Gladstone & O'Connor (2011) note the role of parent-child interactions as key factors in the transmission of risk for psychological difficulties from parent to child. EE, first described by Brown & Rutter, (1966), is an important construct in conceptualising interactions

between family members. EE is often best outlined by describing the measures used to assess it. The Camberwell Family Interview (CFI; Vaughn & Leff, 1976) is frequently used as a measure of the family 'emotional environment' (Hooley, 2007). The interview is designed to elicit carers' attitudes about their relatives' behavior and symptoms, based on content and prosodic variables of speech such as tone, speed, repetition and emphasis. It provides five ratings of EE: criticism, hostility, emotional over-involvement (EOI), warmth and positive comments; based on these a categorisation of High or Low EE can be made.

Five Minute Speech Sample

Subsequent to the CFI, the five-minute speech sample (FMSS; Magana *et al.*, 1986) was developed as a brief measure of EE. The FMSS is based on the CFI but has the advantage of taking less time to administer and code. The FMSS requires relatives to talk about the target relative for five minutes. Specifically, respondents are asked to talk about what kind of person the relative is and how they get along together.

Although hostility is not coded from the FMSS, both criticism and EOI are coded based on the original constructs from the CFI. Critical comments are negative remarks about the relative's behaviour or personality, based on content or tone. High criticism is coded when there are one or more critical comments in the sample, a negative comment on the relationship with the relative, or where the opening statement in the speech sample is critical. Moore and Kuipers (1999) report a high correlation between the number of critical comments rated on the CFI and the number of criticisms rated using the FMSS.

EOI assesses the level of emotional involvement between the respondent and their relative. High EOI is coded when there is evidence of self-sacrificing behaviour/overprotective behaviour, emotional display during the speech sample, expression of very strong feelings of love for the child or a willingness to do anything for the child in the future. Positive remarks are comments in which the person's behaviour or personality is praised or complimented. The FMSS also provides a relationship rating, based on all the relationship information in the sample, which can be positive, negative or neutral. Although Moore and Kuipers (1999) report high agreement (89.7%) in EE classification between the FMSS and the CFI, the potential of the FMSS to underestimate high EE has been noted in a review (Hooley & Parker, 2006). The authors suggest that including borderline ratings of criticism or EOI as evidence of high EE may partly resolve the problem.

Research Findings in Expressed Emotion

EE is the strongest psychosocial predictor of clinical and functional outcome for individuals with schizophrenia (Butzlaff and Hooley, 1998) and an important target of intervention in

treatment studies (Miklowitz, 2004). Criticism is the strongest predictor of the high EE scales, and has been consistently linked to poor outcomes among adult patients with schizophrenia (Butzlaff & Hooley, 1998). EE has also been shown to predict poor outcomes in a range of other disorders including depression (Butzlaff & Hooley, 1998), obsessive-compulsive disorder and agoraphobia (Chambless *et al.*, 2001), and bipolar disorder (Yan *et al.*, 2004; see Wearden *et al.*, 2000)

Similar high EE-poor outcome associations have been found in younger samples. High levels of EE in carer-patient dyads have been associated with poorer outcomes and relapse in young people with schizophrenia (King & Dixon, 1999) and children with mood disorders (Asarnow, Goldstein, Tompson & Guthrie, 1993). Reviews of prospective and retrospective studies have shown that parental EE is a risk factor for long-term outcomes in child and adolescent psychopathology, including the development, course and outcomes of child mental health problems (Wearden, Tarrier, Barrowclough, Zastowney, & Rahill, 2000; Weintraub & Wamboldt, 1996). Hibbs and colleagues (1991) found that the proportion of parent-child dyads that were coded as High EE was higher in families where at least one of the children had a psychiatric disorder compared with nonclinical groups. Parents of children with conduct disorder are more likely to be critical of their child, and maternal warmth has been found to discriminate between clinic-referred and non-referred children (Asarnow, Tompson, Hamilton, Goldstein, & Guthrie, 1994).

Goldberg-Arnold *et al.* (1999) conceptualise high EE as both a stressor for the child with a mental health problem, and also as an interactional variable between parent and child. They suggest that the child's symptomatic behaviour acts as a stressor for parents, this exacerbates EE, and in turn leads to more critical, hostile or over-involved interactions. High EE may also increase the risk of relapse for the child, which can in turn have a negative impact on the parents' emotional well-being (Vostanis & Nicholls, 1995). EE can therefore be seen as both a risk factor for increased parental anxiety and depression and decreased parental well-being, as well as a risk factor for increased mental health problems for the child.

Differential Associations of EE Ratings

The association between EE and childhood problems has been most reliably shown in externalizing behaviours, rather than internalizing behaviours. Differential associations between EOI and criticism have also been noted. Child disruptive behaviour disorders were more frequent in parent-child dyads characterised by high levels of criticism, whereas child anxiety disorders were more often found in parent-child dyads characterized by high levels of EOI (Stubbe, Zahner, Goldstein, & Leckman, 1993). There are mixed findings for EOI in child and adolescent studies; EOI has also been associated with more positive clinical outcomes in

childhood physical health conditions (diabetes; Stevenson, Sensky & Petty, 1991) and for adolescents at risk for the onset of psychosis (O'Brien, Gordon, Bearden, Lopez, Kopelowicz & Cannon, 2006). Across the literature, criticism is more consistently related to children's behavior problems than EOI (Baker *et al.*, 2000; Peris & Baker, 2000; McCarty & Weisz, 2002; Bolton *et al.*, 2003; Nelson *et al.*, 2003). Hastings and Lloyd (2007) propose that the strong association between criticism and outcomes may indicate that criticism is a proxy measure of parenting behaviour; however this remains to be shown in the evidence. McCarty *et al.* (2004) found that critical parents engaged in more negative parenting behaviors whereas EOI was not related to parent behavior.

Psychotic-Like Experiences and Expressed Emotion

It is clear then, why parental EE has been recommended as a target of research concerning 'child-specific psychosocial influences' in childhood disorders (Rutter, 1999). Children presenting with PLEs in late childhood and early adolescence, particularly if the PLE's are distressing, are also likely to be negotiating a variety of developmental stages including independence. Caregiving relationships are likely to be different for a young PLE group compared to older groups with established mental health difficulties, but overlaps have also been found. A prospective, longitudinal birth cohort study in the UK measured maternal expressed emotion using a five-minute speech sample when the child was aged 10 years. The authors report that mothers of children with PLEs had increased levels of EE, although no difference in maternal warmth was found (Polanczyk *et al.*, 2010).

EE research with a specific focus on children who exhibit PLEs could advance what we know about the development and possible effects of parent-child relationships. McFarlane and Cook (2007) found lower levels of EE in patients in the prodromal phase of psychosis than with diagnosed psychosis. However, research on caregiving in psychosis suggests that high levels of EE are already present during the early stages; an estimated 30-50% of the carers of people presenting to early psychosis services record high levels of EE (Meneghelli, Alpi, Pafumi, Patelli, Preti, & Cocchi, 2011; Patterson, Birchwood & Cochrane, 2005; Raune, Kuipers & Bebbington, 2004). Birchwood and Macmillon (1993) noted that most of the changes associated the development of psychosis are observed in the early stages of the illness, for example the deterioration of the individuals social and psychological functioning. These changes also necessitate a reappraisal of family expectations (Gleeson, Jackson, Stavey & Burnett, 1999).

Studies that have focused particularly on individuals at risk for psychosis have found the presence of high EE in one third of their sample of high-risk patients (Meneghelli *et al.*, 2011; average age: 21.8 years), consistent with previous reports in at-risk populations (Hooley & Richters, 1995; Schlosser *et al.*, 2010). Meneghelli and colleagues (2011) found that levels of

EOI were much greater than criticism for both high risk and first episode groups. This predominance of EOI over criticism in prodromal populations has been reported elsewhere (McFarlane & Cook, 2007; O'Brien *et al.*, 2006). In contrast to this trend, O'Brien and colleagues (2006) found that families of adolescents (average age: 16.2 years) with PLEs, (who were in a prodromal phase of psychosis) had equivalent levels of EOI and criticism. However, the overall level of criticism was still lower in this cohort than is generally found in carers of patients with a schizophrenia diagnosis.

Models of caregiving

Much of the research regarding the parents of children with emotional and behavioural problems has been informed by one of two models: 'top-down' models have examined the impact of parental variables on the child's problems, with parental factors viewed as a risk factor for the child. For example, higher levels of parenting stress are related to higher levels of child symptomatology (Nelson, Stage, Duppong-Hurley, Synhorst & Epstein, 2007). Alternatively, 'bottom-up' approaches have investigated the impact of childhood problems on parental strain and stress. For example increased child symptoms have been shown to predict increased parenting stress (Deater-Deckard, 2004; McDonald, Gregoire, Poertner, & Early, 1997). Such research views parent and child factors as having unidirectional influences, however McDonald, Poertner and Pierpont (1999) have proposed that the relationship between parental factors and child factors is bidirectional and multifaceted. The current research will investigate several cognitive and affective variables hypothesised to represent key aspects of the bi-directional inter-relationships of parent and child difficulties.

Cognitive Model of Caregiver Responses in Psychosis

Kuipers and colleagues (2010) have proposed a cognitive model of informal carer relationships in adult psychosis that accounts for the divergent outcomes of positive, EOI and critical/hostile relationships, as outlined in Figure 1. This study will examine whether these inter-relationships are replicated in caregiving relationships in parents and children in community CAMHS.

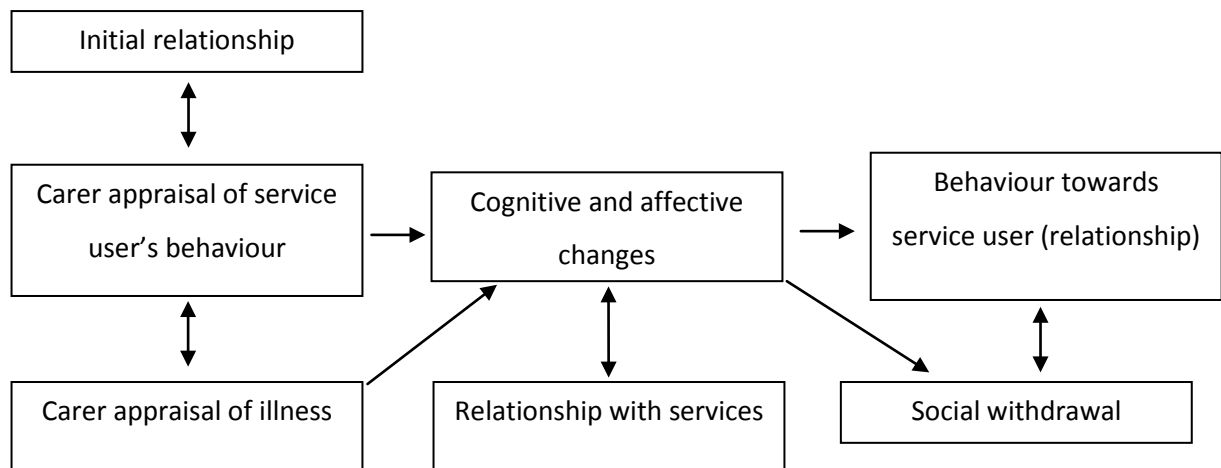


Figure 1: Cognitive model of caregiver responses in psychosis (Kuipers *et al.*, 2010).

Cognitive and affective changes

The literature regarding parental stress and strain emphasises that both affective and cognitive processes are associated with caring for a child with emotional and behavioural difficulties. This may have an adverse impact on parent mood. Tan and Rey (2005) found that the relationship between the mother and child's mood problems were mediated by maternal appraisals of their child as more difficult. The finding of Tan and Rey (2005) may indicate that the more severe the child's symptoms, the higher the level of difficulty experienced by the parent. Alternatively, it may highlight the influence of parental appraisals upon both parent and child mood problems. A third possible explanation is that depressed parents may find it harder to cope and may therefore rate their child as being more difficult. The current sample of parental caregivers is expected to display increased levels of affective disturbance (anxiety and depression). The role of parent appraisals will also be considered in the current research, in line with the cognitive model of caregiver responses (Kuipers *et al.*, 2010).

Parental Appraisals of Child Problems

The attributional theory of emotion (Weiner, 1985) has been applied to understanding EE in parent-child dyads (Bolton *et al.*, 2003). It proposes that the pattern of attributions for others' behaviour mediates an individual's emotional and behavioural responses to that behaviour (e.g. coping strategies and mood). This also reflects cognitive-behavioural theory, in that it is not what occurs (i.e. the child's symptoms or behaviour), but rather the parent's interpretation of what occurs that influences their response, and consequently the parent-child relationship. Caregivers' appraisal of a patients' behaviour, and in particular increased caregiver attributions of controllability to the patient for their behaviour, has been associated with the development of high EE relationships. Dix and Grusec (1985) used attribution theory to show that when parents attribute negative child behaviour to internal, stable characteristics of the child, they

are likely to demonstrate more negative affective and behavioural responses to the child's behaviour than if that behaviour was attributed to external, unstable causes.

Similar findings have been replicated in carers of adults with psychosis; those carers who demonstrated high levels of criticism were more likely than low-criticism carers to believe that patients can control the manifestation of their symptoms (Barrowclough, Johnston & Tarrier, 1994; Hooley, Richters, Weintraub, & Neale, 1987). In addition, parents of patients experiencing their first episode of psychosis who demonstrated high criticism were more likely to make attributions that the young person could control their illness, and to value person-focused criticism in controlling the young person's difficulties (for example, parents sharing their dissatisfaction and frustration with them as a person; McNab, Haslam, & Burnett, 2007). Likewise, Bolton and colleagues (2003) found that high EE mothers were more likely than low EE mothers to believe that the cause of their child's problem was personal to and controllable by the child, and that they also made more 'child-blaming' attributions than low EE mothers.

In addition to appraisals of controllability, carer appraisals of greater negative consequences of the person's illness have been associated with increased carer distress. Caregivers reported increased levels of distress when they perceived the illness as long-term (Onwumere *et al.*, 2008). Recent evidence has found that mothers of children with internalizing disorders tended to generate more catastrophic worries than with children without mental health difficulties (Triantafyllou, *et al.*, 2012). The authors also found that the association between child anxiety and depression and maternal worries remained evident after controlling for maternal anxiety and depression. These results indicate a strong relationship between parental appraisals and child emotional problems. The quality of the parent-child relationship may influence this association. Previous research in adult samples has found that where carers perceive more negative illness consequences for the patient, the patient was more likely to rate the relationship as poor (Barrowclough, Lobban, Hatton, & Quinn, 2001).

Studies have not only looked at the association between parents' appraisals and parent behaviour or the parent-child relationship; they have also investigated the association between parents' appraisals and child behaviours. Two longitudinal studies have found that a mother's hostile attributions for their child's externalizing problems were predictive of the child's conduct problems two to three years later (Nix, Pinderhughes, Dodge, Bates, Pettit, & McFadyen-Ketchum, 1999; Snyder, Cramer, AfFrank & Patterson, 2005). In addition, parental attributions have been linked to dropout rates from parenting programs (Miller & Prinz, 2003), as well as child treatment outcomes (Hoza *et al.*, 2000). This highlights the relevance of parent appraisals in clinical settings. Appraisals of consequences, control and cure have been found to be unrelated to objective measures of illness severity for the patient (Barrowclough *et al.*,

2001). The current study will test the hypothesis that parental appraisals of their child's difficulties as long-term, and with a high magnitude of consequences for the child, and higher perceptions of controllability by the child will be associated with higher levels of parental affective disturbance.

Coping Strategies

Kuipers and colleagues (2010) suggest that, in psychosis, a parent's appraisal of their child's problem will influence parental cognitive and affective changes, which in turn will influence the parent's relationship with their child. This hypothesis is in line with the Cognitive Model of Stress and Coping (Lazarus & Folkman, 1984), whereby cognitive appraisals influence coping which in turn influences outcome (i.e. the parents' relationship with their child). Coping is defined as "*the constantly changing cognitive and behavioural efforts to manage the specific external or internal demands that are appraised as taxing or exceeding the resources of the person*" (Lazarus & Folkman, 1984, p.141). The implementation of coping strategies is thus a cognitive and behavioural response by the parent, influenced by appraisals of their child's problems. The central role of coping in the development of high EE is supported by Chambless and colleagues, who found coping to be the only significant predictor of a subjective measure of high EE (Chambless, Bryan, Aiken, Steketee, & Hooley, 2001).

Parabiaghi *et al.* (2007) found that coping strategies in carers of people with psychosis may become more effective with time. Carers may use less adaptive coping strategies in the early stages of caring, as adjustment to the role and difficulties occurs. Parents of children with recently emerged mental health difficulties could be expected to be undergoing a similar adjustment; their child may require additional care due to emotional and behavioural difficulties, or they may be feeling overwhelmed by the impact of their child's symptoms. As a result these parents may employ less adaptive coping strategies.

Avoidant coping includes behavioural disengagement, mental disengagement, alcohol and drug use, and denial of the problem. Avoidant coping strategies have been proposed as an attempt to shield oneself from overwhelming distress (Rose, Mallinson & Walton-Moss, 2002). High levels of EE, poorer carer functioning and increased carer burden have been linked to avoidant coping in carers of adults with psychosis (Raune, *et al.*, 2004; Dyck, Short & Vitaliano, 1999). Avoidant coping in carers of young people with first episode psychosis was related to levels of carer distress, EOI, and increased burden (Cotton, McCann, Gleeson, Crisp, Murphy, & Lubman, 2013). Onwumere *et al.* (2011) found that avoidant coping was related to distress in carers of people with psychosis, irrespective of the duration of the illness. These findings suggest that carer's avoidant coping strategies are present early in the development of

psychotic difficulties, and are likely persist in the long-term. If unaddressed, avoidant coping can relate to poorer carer outcomes and poorer carer-patient relationships.

O'Brien and colleagues (2009) have found a strong association between parent and child problem-solving approaches, for children at risk (or with recently developed) psychosis. Children may learn and imitate the avoidant problem-solving strategies they observe in parents, including drug and alcohol use. Increased frequency of cannabis use is associated with increased PLEs in adolescents and young adults (Armando, Nelson, Yung, Ross, Birchwood & Girardi, 2010). The use of illicit drugs may negatively impact on the development and prognosis of severe mental health problems (Henquet, Murray, Linszen, & van Os, 2005). High levels of cannabis use have been found in adults with severe mental health problems, and cannabis use was frequently identified as a method of coping for individuals (Graham & Maslin, 2002).

High levels of EE have been associated with another maladaptive coping strategy: carer self-blame (Peterson & Docherty, 2004). Wasserman, de Mamani, & Suro (2012) found a positive association between levels of EE and relatives' feelings of self-blame, as a direct consequence of having a relative with schizophrenia. They found that higher levels of both shame and guilt/self-blame about having a relative with schizophrenia predicted high EE. Bolton and colleagues (2003) found that maternal self-blame had a positive association with EOI in mothers of children with problem behaviours. Dyck *et al.* (1999) found that self-blame coping predicted carer burden. Self-blame is also frequently associated with depression (Meyer, 2001). The current research will examine whether parental use of less adaptive coping strategies (avoidance and self-blame) will be associated with increased affective disturbance in parents.

Perceived Social Support

Perceived social support is the subjective judgement that family and friends would provide affect, aid, and affirmation in the event of future stressors (Taylor, 2011). People with high perceived-support believe that they can count on their family and friends to provide quality assistance during times of trouble. This assistance may include helping the stressed person feel more relaxed, expressing care and acceptance, being dependable and offering consolation. In stressful times, social support can help reduce psychological distress (e.g., anxiety or depression; Taylor, 2011). Low levels of social support have been found to be related to increased depression (Koizumi *et al.*, 2005). A lack of social support has even been associated with immunological decline among caregivers (Kiecolt-Glaser & Glaser, 1994). A review of the literature concluded that beliefs about the availability of support may actually appear to exert stronger effects on mental health than the actual receipt of support does (Taylor, 2011). This

'invisible' support network can be held in mind, buffering an individual against stress without ever having to recruit to their networks in active ways.

Increased levels of social support for parent caregivers are associated with lower levels of parental distress and higher levels of adaptive coping. Brannan and Heflinger (2001) report that social support has a protective or bolstering role on caregiver psychological distress in parents of children with emotional and behavioural disorders. Social support has also been found to be a protective factor against parental strain when raising a child with behavioural problems (Breevaart & Bakker, 2011). This is consistent with previous research that found that social support might boost coping strategies for families of children with emotional and behavioural challenges (McDonald *et al.*, 1997; 1999). Specifically, Magliano and colleagues (2003) found that higher levels of social support encouraged more proactive and effective coping in carers of people with psychosis. In first episode psychosis groups, carers reporting access to a confidant also reported more positive caregiving experiences (Boydell *et al.*, 2013).

There has been concern that measures of social support may overlap with measures of self-reported psychological distress, with each variable potentially measuring a portion of the same variance, (e.g. variance in well-being; Barrera, 1986). Turner, Frankel, & Levin (1983, cited in Barrera, 1986) used factor analysis to determine if perceived social support and psychological distress items could be differentiated. The perceived availability of social support and psychological distress were found to represent distinct factors. Perceived social support availability will be measured in the current study, by asking participants to name specific people in their social network that they could turn to for affect, aid, and affirmation, if in need. This taps in to the 'invisible' support network of the parent, and is proposed to be more conceptually distinct from measures of psychological distress than other measures of social support, such as social support satisfaction.

Parent-Child Relationship

Dix and Lochman's (1990) 'cognitive-emotional model' of parenting reflects the relationships proposed in the Kuipers *et al.* (2010) model: mood disturbance in parents is hypothesised to mediate the relationship between their appraisals for child behaviour and the parent-child relationship. Evidence from Bolton and colleagues (2003) supports this hypothesis; they found that maternal depressed mood was a predictor of high EE in mothers of children with problem behaviours. The current study hypothesises that increased parent mood disturbance is related to increased incidence of high EE in parent-child dyads.

Hypotheses

Hypotheses concerned the applicability of the cognitive model of caregiving to parent-child relationships in a group of clinically referred children, and the association of family environment with child difficulties, both in general, and specifically in relation to PLE severity.

The primary hypothesis to be tested was whether there was an association between parent-child relationships and parental affective disturbance. The second set of hypotheses concerned the processes underlying this association, firstly the association of parental appraisals, coping and social support with parental distress, and secondly their association with EE. The final set of hypotheses investigated the association of parental affective disturbance, EE, and mediating psychological processes, with severity of child difficulties, both in general and specifically severity of PLEs. Both parent and child ratings were considered.

Hypothesis One

Parents who report high EE will have significantly higher levels of anxiety and depression, than those who report Low EE.

Hypothesis Two

Parent affective disturbance will be associated with more threatening parent illness appraisals, maladaptive coping strategies and lower levels of social support.

The extent to which psychosocial variables are predictive of the parent-child relationship will also be investigated, in line with the Cognitive Model of Caregiving outlined in Figure 2.

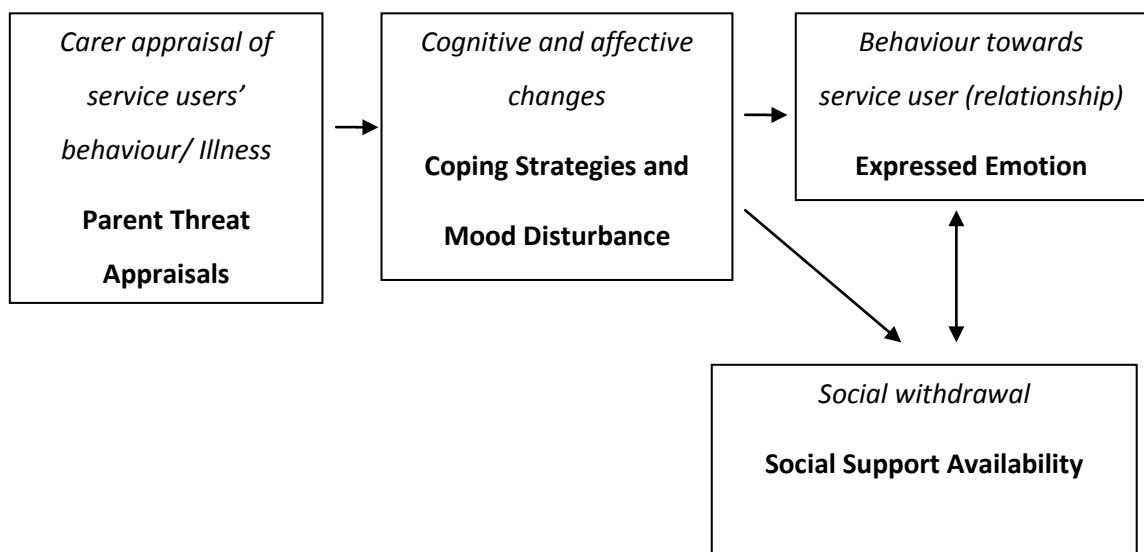


Figure 2: Hypothesised relationships between parent variables (based on Kuipers *et al.*, 2010). *Italicised font*= Cognitive Model of Caregiving; **Bold font**= Current variable of interest.

Hypothesis Three

Increased child difficulties will be associated with increased parent affective disturbance, more threatening appraisals, less adaptive coping, lower levels of available social support, and greater likelihood of high EE in the parent-child relationship.

Method

This research was conducted in the context of the ‘Coping with Unusual Experiences in Children Study’ (CUES). CUES is a pilot randomised controlled trial (RCT) of a Cognitive Behavioural Therapy (CBT) protocol for young people reporting PLEs and emotional distress, funded by Guy’s and St Thomas’ Charity. CUES is based within the South London and Maudsley (SLAM) NHS Foundation Trust Community Child and Adolescent Mental Health Service. The service provides assessment and interventions for children with moderately severe emotional and behavioural problems in the absence of a diagnosed mental health disorder.

Ethical approval for the main RCT was obtained from the London Hampstead Research Ethics Committee and an amendment was approved to incorporate the current research (REC Reference 11/LO/0023; Appendix 1). Research and Development approval was granted by the local NHS Trust (reference R&D2011/028) and the CAMHS Clinical Academic Group.

Recruitment

Young people aged between eight and 14 who were referred to CAMHS in SLAM, and placed on the waitlist were approached to participate in the CUES study. These children were considered by CAMHS not to require urgent intervention, and, at the time of the start of the study, would usually wait 3-6 months before receiving CAMHS input. A letter addressed to the child’s primary carer was sent to invite both the young person and their parent or carer to participate in the study (Appendix 2). The letter included an information sheet for parents/carers (Appendix 3) and a children’s version (Appendix 4), copies of the consent (Appendix 5) and assent forms (Appendix 6) and a stamped addressed envelope. The letter stated that a researcher would contact the family to discuss the study, unless they requested not to be contacted. This call was usually made about a week after receipt of the letter, and the researcher discussed the project with the family to find out if they would like to take part. If the family expressed an interest in participating, a meeting to discuss the research was arranged. Informed consent was sought at this meeting, after the researcher explained the information sheets to the parent and child, checked their understanding and provided opportunities to ask questions. The child’s treatment and care from CAMHS was not affected by participation in CUES. Once they reached the top of the waitlist their care and treatment continued as normal. The researcher emphasised the prerogative of the parent to abstain from completing the parent questionnaires pertaining to this study, without the need to give any reason or explanation and without this affecting their child’s on-going participation in CUES, if desired, or any present or future treatment they, or their child, would receive. Once consent was given, arrangements were made to start the assessments. Every effort was made to be flexible with timings of appointments.

CUES Study Protocol

The parent and child measures pertaining to the current study were administered at the baseline screening or pre-treatment assessment as part of the broader battery of assessment. If risk issues were identified during the research screening or subsequent involvement the clinical team were alerted to provide appropriate advice or reassess the referral or the researcher took appropriate steps to ensure crisis and contingency plans were in place. The CAMHS team held care co-ordination responsibilities for all participants during the research.

Criteria for the Current Study

The current study was concerned only with data obtained at the screening and pre-treatment phase of the broader CUES project. This phase of the data collection was to identify those children who were eligible for the CUES Randomised Control Trial (RCT; see Appendix 7 for outline of RCT), but also to gain a more detailed understanding of the variations in child and parent psychosocial profiles associated with children presenting with PLEs and other emotional and behavioural difficulties.

Inclusion and Exclusion Criteria

Children aged 8-14 referred to CAMHS and placed on the service waitlist were eligible for the study, along with their parent or other primary caregiver. Parents were required to have sufficient English language skills to complete the measures. Audio recordings of the information sheets and researcher assistance were provided to parents with poor literacy or sight difficulties. Parent-child dyads were only included if the young person provided informed assent, and the parent/caregiver provided informed consent. Exclusion criteria included those younger than 8 or older than 14 at the time of referral.

Demographic and clinical variables

Demographic details and objective indices of the emotional and behavioural difficulties for each child were collected as part of the on-going RCT. This included age, sex, ethnicity and any history of familial mental health problems, as reported by parents and corroborated in the clinical record.

Measures

All assessment measures are included in Appendix 8 and Appendix 9.

Parent Well-being

Warwick-Edinburgh Mental Well-Being Scale (WEMWBS; Tennant *et al.*, 2007)

The WEMWBS was used to assess parents' well-being. It is a 14-item scale covering both hedonic and eudaimonic aspects of mental health including positive affect (feelings of optimism, cheerfulness, and relaxation), satisfying interpersonal relationships and positive functioning (energy, clear thinking, self acceptance, personal development, competence and autonomy). Items refer to the past two weeks and are rated on a 5-point Likert scale (none of the time, rarely, some of the time, often, all of the time). The overall score is calculated by totalling the scores for each item and a higher score indicates a higher level of mental well-being. Acceptable psychometric properties have been reported (e.g. Tennant *et al.*, 2007) and the instrument is robust across cultures (Stewart-Brown, 2013). The Public Health Outcomes Framework (Department of Health, 2012) includes an indicator on subjective well-being, and uses WEMWBS to measure this.

Child PLEs

Psychotic-like Experiences Questionnaire (PLEQ, Laurens *et al.*, 2007; 2011)

The presence of children's PLEs was assessed using the PLEQ. Child self-report and parent-reported versions were administered. The PLEQ consists of nine questions, rated on a three point scale (Not true, Somewhat true, or Certainly true). Five of these questions were adapted by Laurens *et al.* (2007) from the Diagnostic Interview Schedule for Children (Costello, Edelbrock, Kalas, Kessler & Klaric, 1982). The items assessed the occurrence of hallucinatory experiences and unusual ideas in the last two weeks (e.g., "Have you ever heard voices other people could not hear?"). Responses were rated on a three point scale (Not true [0], Somewhat true [1], Certainly true [2]), and summed to provide a conviction subscale. Parent-report questions substituted the word 'you' with 'your child'. Any child or parent indicating the presence of a PLE (i.e. a 'Somewhat true' or 'Certainly true') response to any of the PLE items was asked to further indicate;

1. How often the experience happened over the last 2 weeks (frequency subscale),
2. Whether the experience had upset them in the last two weeks or (distress subscale),
3. If it had caused them any difficulty at home or in school in the last two weeks (impact subscale).

The frequency of the PLE was assessed on a four point scale (Not at all [0], Only once [1], Two-four times [2], or Five or more times [3]). Responses to the distress and impact subscale questions were indicated on a similar four point scale (Not at all [0], Only a little [1], Quite a lot [2] or A great deal [3]). A summary variable was created by summing the child/parent's report of conviction, frequency, impact and distress associated with PLEs in the two weeks prior to assessment (Total PLE severity, range 0-99).

Child Emotional and Behavioural Difficulties

Strengths and Difficulties Questionnaire (SDQ, Goodman, 1997)

The SDQ is a questionnaire developed for screening 3-16 year olds for behavioural and emotional difficulties. A parent-report and self-report version was used in the current research. The child self-report questionnaire has been validated for use with children and adolescents from 8 years (Goodman, Meltzer & Bailey, 1998; Muris, Meesters, Eijkelenboom & Vincken, 2004). The SDQ has been reported to be both valid and reliable (Goodman, 2001), and suitable for use with clinical samples (Goodman, Lamping & Ploubidis, 2010). The SDQ measures emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and pro-social behaviours. Each item is rated on a three point scale (not true, somewhat true, or certainly true). A total difficulties score (range 0-40) is calculated by summing the totals of emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems (Goodman, 1997).

Parent-Child Relationship

Expressed Emotion: Five-Minute Speech Sample (Magaña *et al.*, 1986)

EE was measured using the Five Minute Speech Sample (FMSS). Parents completed the FMSS according to the method described by Magana *et al.* (1986). Speech samples were transcribed and coded by the author, as primary coder. The primary coder was initially trained to criterion level by the supervisor (JO), an experienced trainer and rater of EE. Seventeen speech samples (seven independent of the current study), were rated and discussed by the author, a research assistant and the FMSS trainer (JO), until agreement was reached on both scales. The trainer independently rated a subsample of 10 speech samples (30%), in order to confirm adequate inter-rater reliability. The remaining speech samples were coded by the author.

Using guidelines provided by Fleiss (1981) and Cicchetti and Sparrow (1981), Kappa values indicated an excellent level of agreement on the Criticism dimension ($\kappa = 0.87$) and a good level of agreement on the Emotional Over-Involvement dimension ($\kappa = 0.70$). Inter-rater agreement on individual subscales was also examined. An excellent level of agreement was found for the Relationship ratings and Presence of Dissatisfaction ($\kappa = 0.85$; $\kappa = 1.00$, respectively). A good level of agreement was found for the Initial Statement ($\kappa = 0.70$) and for the Presence of Self-sacrificing, Overprotective or Lack of Objectivity ($\kappa = .62$). For ratings of the presence of Emotional Display agreement was 100%, however Kappa was poor due to the constant response of both raters. Intra-class correlations were calculated for ratings of the number of Criticisms (ICC = .88) and number of Positive Remarks (ICC = .84). In addition, agreement was 90% on Statements of Attitude; however the ICC was poor due to the constant response of one rater. Overall ratings of EE classification (High EE versus Low EE) was excellent ($\kappa = .80$).

The FMSS was chosen as a measure of EE, having balanced the limitations against its pragmatic utility. In a review of the literature on measures of EE, Van Humbeeck, Van Audenhove, Pieters, De Hert, and Storms (2002) noted that the predictive power of the FMSS remains unclear. They highlight that a low EE score on the FMSS does not imply a Low EE score on the 'gold standard' modified Camberwell Family Interview (CFI; Vaughn & Leff 1976). In a later review, Hooley and Parker (2006) concluded that while the FMSS is slightly less sensitive than the CFI methodology, it had the advantage of being considerably more time efficient. Hooley and Parker (2006) also note that the FMSS has gained much prominence in the field of child psychopathology research (Jacobsen, Hibbs & Ziegenhain, 2000; Peris & Baker, 2000; Wamboldt, O'Connor, Wamboldt, Gavin, & Klennert, 2000).

The developers of the FMSS (Magana Amato, 1993) have suggested a modification in the coding system when the FMSS was completed by parents regarding their young children, since the FMSS was originally developed for families talking about an adult family member. This modification re-classifies the borderline classifications as High EE. This coding methodology was used in the current research, in line with previous research with children (Jacobsen, Hibbs & Ziegenhain, 2000).

Parent Social Support

Social Support Questionnaire (SSQ6; Sarason, Shearin, Pierce & Sarason, 1987)

The availability of parental social support was measured using the SSQ-6, a six-item measure that assesses the quantity of social support available and the individual's level of satisfaction with their social support (Sarason *et al.*, 1987). The measure of social support availability will be used in the current study, for reasons outlined in the introduction (p. 28). The SSQ6

demonstrates high internal consistency (Sarason *et al.*, 1987). It has been used to assess levels of social support in families of people with schizophrenia (Chien, Thompson & Norman, 2008), as well as carers of people with other psychiatric conditions (Coomber & King, 2012).

Parent Threat Appraisals

The Brief Illness Perception Questionnaire (Brief IPQ: Broadbent, Petrie, Main & Weinman, 2006).

The IPQ was used to assess parents' appraisals of their children's problems. The Brief IPQ is a standardised questionnaire assessing cognitive and emotional illness representations. The IPQ has been shown to have good test-re-test reliability and concurrent validity with more lengthy measures of illness perceptions (Broadbent *et al.*, 2006). It has been previously used to assess the appraisals of carers of people with psychosis (Berry, Barrowclough & Wearden, 2009; Tomlinson, Onwumere & Kuipers, 2013). The Brief IPQ was adapted for caregivers. As suggested by the authors, the word "illness" was replaced by "child's problems" (Broadbent, n.d.). Consequence and control items were asked both for the child (e.g. How much do you think *your child* can control their problem) and the caregiver themselves (i.e. how much do you think that *you* can control your child's problems). The measure consisted of ten items, rated on an 11-point (0-10) response scale. Seven of the items assessed cognitive illness representations (Personal Consequences, Child Consequences, Timeline, Personal Control, Child Control, Treatment Control; Identity). Two items assessed emotional representations (Concern and Emotional Response). One item assessed Illness Understanding. High scores represent strongly held beliefs. According to Broadbent (n.d), the overall score of all items reflects an evaluation of the degree to which illness is perceived as threatening. Higher scores indicate a more threatening perception of illness (Cronbach's $\alpha = 0.73$). Klien (1999) suggests that $\alpha = 0.70$ - $.80$ represents good reliability. Causal attributions were assessed through open-ended questions at the end of the brief IPQ, asking parents to list the three most important causes of their child's illness. Ayers *et al.* (2007) note that open-ended questions have the advantage that responses are not limited to the listed items.

Parent Affective Disturbance

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)

The HADS was used to assess levels of parental affective disturbance. It consists of 14-items measuring two subscales: anxiety and depression (seven items each). Items are rated on a zero- to three- point scale, indicating the strength of agreement with each item. Thus, scores for each subscale ranged from 0 to 21. It has been widely used in studies of relatives of patients with psychosis (e.g. Oldridge & Hughes, 1992; Fortune, Smith & Garvey, 2005) and has

demonstrated acceptable psychometric properties. In a review of the measure, a cut-off score of ≥ 8 on either subscale suggested probable clinical disorder (Bjelland, Dah, Tangen Haug & Neckelmann, 2002). This cut-off was used in the current study to assess levels of anxiety and depression in parents. The anxiety and depression subscales may be summed together to provide a total score, regarded as a global measure of psychological distress (Roberts, Bonnici, Mackinnon, & Worcester, 2001; Aben, Verhey, Lousberg, Lodder & Honig, 2002).

Parent Coping

The Coping Orientations to Problems Experienced (COPE) Inventory (Carver, Scheier, & Weintraub, 1989)

The COPE was used to assess coping strategies used by parents. It is a multidimensional coping inventory that assesses 15 subscales: active coping, planning, suppression of competing activities, restraint, seeking social support for instrumental reasons, emotional reasons, positive reappraisal, turning to religion, acceptance, humour, denial, focus on and ventilation of emotions, behavioural disengagement, mental disengagement, and alcohol/ drug use. An additional subscale pertaining to self-blame was included from the Brief COPE (Carver *et al.*, 1997). Each subscale has two items. Parents were asked about their style of coping with the problems associated with their child's mental health during the last 3 months. Parents rated their frequency of use of these strategies on a 4-point scale, ranging from 1 (*not at all*) to 4 (*doing a lot*).

Similar to previous studies (e.g. Kuipers *et al.*, 2006; Onwumere *et al.*, 2011; Raune, Kuipers & Bebbington, 2004), behavioural disengagement, mental disengagement, alcohol/drug use, and denial subscales will be summed to represent a general 'avoidant' coping scale (score range, 4 to 16). The COPE subscales have demonstrated acceptable reliability ranging from Cronbach's $\alpha = .50$ to $.90$ (Carver, 1997).

Assessment Procedure

Young people completed the measure of PLEs using an online survey (SelectSurvey.NET 2.8.5), in the presence of the researcher, with reading and explanation by the researcher as required. Parent responses were collected using paper questionnaires, which were later entered on the online survey. The online survey collated responses for export into SPSS for analysis.

Appointments with parents and children took place at the child's home or in the clinic. Child screenings were sometimes completed in the child's school. In all settings it was ensured that a quiet room was obtained for the sole purposes of testing, to ensure privacy. Parents had the option of staying in the same room as their child while both parties were completing measures or going into another room with a researcher. In all cases the Five Minute Speech Sample

(Magana *et al.*, 1986; outlined below) was administered to parents in a room separate to their child. An audio recording of the parents' five-minute speech sample was used.

Parents were generally able to complete all measures in one assessment session. Children's assessments were divided into three assessment sessions to allow for the additional CUES baseline measures to be administered. The PLE measure was not usually administered to the child in the first meeting with the researcher, to ensure the opportunity to facilitate engagement and build rapport prior to administration.

Power

Power was calculated using *G*Power 3*. Bolton *et al.* (2003) reported an effect size (ES) equivalent to a Spearman's ranked correlation of $\rho=.46$ for the association between High versus low EE and affective disturbance in parents. Power analyses revealed that a sample size of 35 provided a power of .8 to detect the same ES for the relationship between EE and affective disturbance significant at the .05 level, two-tailed (hypothesis one). Fortune, Smith and Garvey (2005) reported an ES of $r=.41$ for the association between affective disturbance and self-blame coping. Power analyses revealed that a sample size of 44 provided a power of .8 to detect an ES $r=.4$ for the relationship between parental mood disturbance and self-blame coping significant at the .05 level, two-tailed.

Statistical Analyses

All statistical analyses were carried out using SPSS for Windows (Version 18.0). The assumption of normal distribution was tested for each key variable using the Kolmogorov-Smirnov test of normality, in conjunction with a visual inspection of the quantile-quantile plots and the values of skew and kurtosis. Z-scores were examined to identify any outliers above 3.29 (Field, 2009). One outlier was identified in the social support availability data; this was replaced with the mean plus two standard deviations. This data point remained the largest for that measure (as advised by Field, 2009). A number of variables were not normally distributed (Child rated PLE severity, Parent self-blame, Parent threat appraisals and Parent SSQ satisfaction), and therefore non-parametric correlation analyses were conducted (Spearman's rank correlations). A small amount of data was missing due to participant time constraints, fatigue, or participant inattention. Details of missing data are given in Appendix 10. T-tests, chi-square and correlation analyses showed no significant relationships of parent or child outcome measures with parent or child age, ethnicity, or previous family mental health service contact (t values $\leq .02$; [p values $\geq .398$]; r_s values $\leq .17$ [p values $\geq .258$]; $\chi^2 \leq 1.37$ [p values $\geq .241$]; details are given in Appendix 11).

The association between parent mood disturbance and EE status (hypothesis one) was examined using point-biserial correlations (r_{pb}). Binary logistic regression analyses subsequently assessed the independent associations of anxiety and depression with EE status. Associations between parent mood disturbance, coping, threat appraisals and social support (hypothesis two) were examined using correlational analyses, followed by regression models. Exploratory binary logistic regression analyses were used to test the applicability of the cognitive model of caregiving to this group. Finally, the association between child difficulties and parent psychosocial variables (hypothesis three) was examined using correlational analyses and regression models.

All tests were two-tailed. Multiple tests were conducted. However, as there is no commonly agreed approach to accounting for multiple tests, and possible problems with some strategies such as increasing Type II error (Cook & Farewell, 1996; Perneger, 1998; Rothman, 1990), a decision was made not to adjust for multiple testing. Rather, unadjusted p -values are reported with the limitation of multiple testing acknowledged in the relevant discussion areas; p values between 0.01 and 0.05 are treated as trends towards significance. Unique contribution in regression models was indexed using sr^2 (part r^2). Multicollinearity was within acceptable limits: no correlations between the independent variables exceeded .70 (Ganzach, 1998), except for the correlation between parental mood measures and this has been addressed in the analysis; variance inflation factor values were ≤ 10 ; tolerance values were $\geq .1$ (Menard, 1995).

Results

Participants

The sample consisted of 44 (93.2% female) caregivers of CAMHS referred children, with a mean age of 42.01 years ($SD = 8.60$, range 28.68 -60.53). Table 2 provides a summary of the demographic variables of the sample. The majority of caregivers were the mothers of the referred child (86.4%). White ethnic backgrounds were the most frequently reported (52.3%), followed by Black or Black British (40.9%). The majority of families had English as their first language (97.0%). Many had experience of another family member with a mental health difficulty (i.e. not the referred child; 75.0%). The mean age of the 44-paired children (63.6% male) was 11.61 years ($SD = 1.99$, range 8.13- 14.67).

Table 2: Summary of background variables ($N=44$, except where indicated)

Variable	% (n)
<i>Carer Demographics</i>	
Gender	
Male	6.8 (3)
Female	93.2 (41)
Ethnicity	
White British/ Irish/ Other white	52.3 (23)
Black British/ Afro-Caribbean/ Other black	40.9 (18)
Asian/ Asian-British	2.3 (1)
Mixed Heritage	4.5 (2)
Relationship to Child	
Mother	86.4 (38)
Father	6.8 (3)
Aunt	2.3 (1)
Grandmother	2.3 (1)
Legal Guardian	2.3 (1)
English as first language ($n=33$)	
Yes	97.0 (32)
No	3.0 (1)
Family mental health history ($n=40$)	
Yes	75.0 (30)
No	25.0 (10)
<i>Child Demographics</i>	
Gender	
Male	63.6 (28)
Female	36.4 (16)

Depression, Anxiety and Well-being of Caregivers

Just under half of parents (43.2% $n=19$) displayed signs of clinical depression (≥ 8 score on the HADS). Overall, the mean HADS-D score for the sample was just under the clinical threshold ($M=7.52$, $SD=4.78$). Similarly, a HADS-A cut-off score of ≥ 8 revealed 68.2% ($n=30$) of the sample to display signs of clinical anxiety. The mean HADS-A score for the sample was over the clinical threshold ($M=10.07$, $SD=4.90$). The well-being scores of parents was low, with a median of 40.5 ($M = 38.52$; $SD=12.53$), compared with the national median of 52.0 and national tenth centile score of 39.0 (Bryson, Green, Bridges & Craig, 2012).

SDQ and PLE Scores for Children

The mean score for the child self-report total SDQ was slightly raised, compared to national population norms (Goodman *et al.*, 2010). It falls within the 'borderline' range and may reflect clinically significant problems ($M= 16.16$, $SD= 5.80$). The mean total SDQ score reported by parents was 18.31 ($SD= 6.66$). This represents a score in the 'High' range, indicating a substantial risk of clinically significant problems, based on parent reports (Goodman *et al.*, 2010).

Eighty-two per cent of children ($n=33$) self-reported an experience of one or more PLEs in the last year. Seventy per cent ($n= 28$) reported that they had experienced a PLE in the last two weeks. Over a third of children (37.5%, $n= 15$) experienced 'Quite a lot' or 'A Great Deal' of upset as a result of a PLE experienced in the last two weeks. A third of children (32.5%, $n= 13$) reported 'Quite a lot' or 'A Great Deal' of impact on their life at home or at school as a result of a PLE in the last two weeks. A table outlining the descriptive statistics, prevalence (detailed by response option), and associated distress and impact for the nine PLE items is located in Appendix 12.

In contrast, only 48.8% ($n=21$) of parents reported that their child had experienced a PLE in the last year, and 40.0% ($n=17$) of parents reported that their child had experienced a PLE in the last two weeks. A quarter of parents (25.6%, $n= 11$) felt that their child had experienced 'Quite a lot' or 'A Great Deal' of upset as a result of a PLE experienced in the last two weeks. Just under a quarter of parents (23.3%, $n= 10$) reported that their child had experienced 'Quite a lot' or 'A Great Deal' of impact on their life at home or at school as a result of a PLE in the last two weeks.

Parent Social Support

The average number of available social supports, reported by parents, was 2.44 ($SD=1.64$; range: 0-5.72). The average level of satisfaction with this social support was 5.00 ($SD= 1.11$; min-max: 0-6; higher scores represent higher levels of satisfaction).

Expressed Emotion

The majority of dyads ($n = 28$) were rated as being high EE on the FMSS. A detailed breakdown of categories and dimensions is presented in Table 3.

Table 3: Expressed emotion categories for participants ($N=35$).

Rating	<i>n</i>	%
Low EE	7	20.0
High EE	28	80.0
<i>Borderline EOI</i>	<i>1</i>	<i>2.9</i>
<i>Borderline critical</i>	<i>10</i>	<i>28.6</i>
<i>Borderline EOI and borderline critical</i>	<i>2</i>	<i>5.7</i>
<i>EOI</i>	<i>2</i>	<i>5.7</i>
<i>EOI and borderline critical</i>	<i>3</i>	<i>8.6</i>
<i>Critical</i>	<i>6</i>	<i>17.1</i>
<i>Critical and borderline EOI</i>	<i>0</i>	<i>0.0</i>
<i>EOI and critical</i>	<i>4</i>	<i>11.4</i>

EE= Expressed Emotion; EOI= Emotional Over Involvement

Parental Coping Strategies

Self-blame coping was the most frequently used coping strategy, followed by active coping strategies. Denial was used least frequently by parents to cope with the problems. The average mean score for avoidant coping was 14.98 ($SD= 3.74$). Mean scores for each of the coping strategies is outlined in Table 4. A higher score represents a more frequent use of the strategy.

Table 4: Means and Standard Deviations for Coping Strategies.

Coping Strategies	Min-Max	<i>M (SD)</i>
Self-blame	2-8	5.64 (2.06)
Active Coping	2-8	5.61 (2.07)
Emotional Support	2-8	5.56 (1.93)
Instrumental Support	2-8	5.41 (1.72)
Venting	2-8	5.39 (1.94)
Planning	2-8	5.11 (2.04)
Suppression of Competing Activities	2-8	5.00 (1.67)
Acceptance	2-8	4.98 (1.96)
Self Distraction	2-8	4.95 (1.66)
Positive Reframe/Growth	2-8	4.80 (2.00)
Restraint	2-8	4.53 (1.68)
Behavioural Disengagement	2-8	4.41 (2.02)
Religion	2-8	4.02 (2.30)
Humour	2-7	3.14 (1.50)
Substance Use	2-8	2.86 (1.56)
Denial	2-8	2.75 (1.46)
Total Avoidant Coping	8-25	14.98 (3.74)

Threat Appraisals

Parents reported high levels of concern about their child's problems, and being highly emotionally affected by the problems. They reported low belief in their own ability to control their child's problems, and low beliefs in the ability of the child to control their own problems. In answering the open-ended causal questions, 61.1% ($n= 21$) of parents cited causes related to parenting. Means for each of the illness perception subcategories is presented in Table 5. Higher total IPQ scores represent a more threatening view of the illness.

Table 5: Means and Standard Deviations for Threat Appraisals

Threat Appraisals	Min-Max	<i>M (SD)</i>
Concern	1-10	9.09 (1.70)
Emotional Representation	0-10	8.20 (2.58)
Parent Consequences	1-10	8.00 (2.16)
Treatment Control	0-10	7.84 (2.12)
Child Consequences	0-10	7.36 (2.26)
Identity	0-10	7.27 (2.36)
Child Control	0-10	6.43 (2.63)
Personal Control	0-10	6.39 (2.57)
Timeline	0-10	6.36 (2.42)
Coherence	0-10	4.84 (3.31)
Total Threat Appraisals	22-90	66.11 (13.18)

Hypothesis One

Parents who report high EE will have significantly higher levels of anxiety and depression, than those who report Low EE.

A significant relationship between EE status and anxiety ($r_{pb} = .39$, $p = .021$) was found. Those categorised as high EE were more likely to have higher levels of anxiety. Those categorised as high EE were also significantly more likely to have higher levels of depression ($r_{pb} = .46$, $p = .006$).

Depression and anxiety measures were highly correlated ($r_s = .67$, $p < .001$). Thus, these constructs were analyzed in separate binary logistic regression analyses to avoid multicollinearity (Morrow-Howell, 1994), and to allow us to gain a more valid assessment of the unique predictive power of each independent variable. Expressed Emotion categorisation was significantly related to anxiety ($\chi^2_{df=1} = 4.45$, $p = .035$). For every point increase in anxiety levels, the odds of being in the EE category increased by 1.32 (95% CI = 1.02-1.71; Table 6).

Table 6: Binary Logistic Regression Analyses Predicting the Odds of Scoring High on Expressed Emotion based on Levels of Parental Anxiety.

Predictor	B (SE)	95% CI for Odds Ratio		
		Lower	e^b (odds ratio)	Upper
Constant	-.85 (1.02)			
Anxiety	.28* (.13)	1.02	1.32	1.71

Note: Pseudo $R^2 = .0 .26$ (Nagelkerke). Model $\chi^2 (1) = 4.45$, $p = .035$. * $p < .05$.

Expressed Emotion categorisation was significantly related to depression ($\chi^2_{df=1} = 5.75$, $p = .016$). For every point increase in depression levels, the odds of being in the EE category increased by 1.55 (95% CI = 1.08-2.23; Table 7).

Table 7: Binary Logistic Regression Analyses Predicting Odds of Scoring High on Expressed Emotion based on Levels of Parental Depression.

Predictor	B (SE)	95% CI for Odds Ratio		
		Lower	e^b (odds ratio)	Upper
Constant	-.84 (.86)			
Depression	.44* (.18)	1.08	1.55	2.23

Note: Pseudo $R^2 = 0 .38$ (Nagelkerke). Model $\chi^2 (1) = 5.75$, $p = .016$. * $p < .05$.

Hypothesis Two

Parent affective disturbance will be associated with more threatening parent problem appraisals, maladaptive coping strategies and lower levels of social support.

Parental affective disturbance was associated with less adaptive caregiver coping (avoidance). Higher levels of parental anxiety were associated with avoidant coping, ($r_s [44] = .35, p = .020$). Avoidant coping was not significantly related to levels of parental depression. Neither anxiety nor depression was associated with self-blame coping (Table 8).

Parental affective disturbance was associated with increased parent threat perceptions about their child's difficulties (chronicity, controllability, consequence and total threat appraisals). Increased levels of parental anxiety and depression were both significantly associated with increased threat perceptions ($r_s [44] = .51, p < .001$; $r_s [44] = .49, p = .001$, respectively). Increased levels of parental anxiety and depression were also associated with parents' appraisals of increased problem chronicity and decreased problem controllability. Parental anxiety was related to increased perceptions that problems would have severe consequences for their child (Table 8).

Lower availability of social support was significantly associated with higher levels of depression ($r_s [40] = -.42, p = .007$).

Table 8: Spearman's Correlations between Parent Mood and Psychosocial variables.

	2	3	4	5	6	7	8	9
1. Parent Anxiety	.67**	.35*	.24	.43**	.30*	.31*	.51**	-.30
2. Parent Depression		.25	.01	.44**	.32*	.11	-.49**	-.42**
3. Avoidant Coping			.22	.14	.02	.14	.22	-.04
4. Self-blame				-.04	.04	-.01	.13	.01
5. Timeline Appraisals					.55**	.27	-.65**	-.15
6. Controllability Appraisals						.54**	.74**	-.25
7. Consequence Appraisals							.70**	.02
8. Threat Appraisal								-.21
9. Social Support Availability								-

* $p < .05$; ** $p < .01$, two-tailed.

Parent psychosocial variables (threat appraisals, avoidant and self-blame coping strategies and social support availability) were regressed on to each of the parent mood outcomes separately. For anxiety, the variables accounted for 40.7% of the variance ($F(4,35) = 5.99$, $p = .001$). Parents' threat appraisals was the only significant predictor, uniquely accounting for 14.1% of the variance in anxiety ($\beta = .42$, $p = .007$; Table 9).

Table 9: Linear Regression Predicting Anxiety.

Predictor Variable	R^2	sr^2	St β
	.41		
Social Support Availability		.03	-.17
Avoidant Coping		.01	.09
Self-blame Coping		.07	.27
Threat Appraisals		.14	.42**

** $p < .01$.

Parent psychosocial variables (threat appraisals, avoidant and self-blame coping strategies and social support availability) accounted for 30.7% of the variance in depression ($F(4,35) = 3.88$,

$p = .010$). Once again, only parents' threat appraisals significantly predicted depression, uniquely accounting for 15.4% of the variance ($\beta = .44$, $p = .008$; Table 10).

Table 10: Linear Regression Predicting Depression.

Predictor Variable	R^2	sr^2	St β
	.41		
Social Support Availability		.07	-.28
Avoidant Coping		.05	.02
Self-blame Coping		.01	-.07
Threat Appraisals		.15	.44**

** $p < .01$.

Exploratory Analyses

Regression analyses examined if parent psychosocial variables were predictive of the parent-child relationship, in line with the cognitive model of caregiving proposed by Kuipers *et al.* (2010). Hierarchical binary logistic regression analysis would have been the preferable method of testing the model; however this was not feasible due to the small sample size and the small number of Low EE parents (only 7 events). Given this limitation, separate binary logistic regressions were undertaken to examine if parental threat appraisals, avoidant coping, social support availability and overall affective disturbance predicted levels of expressed emotion in the parent-child relationship.

Expressed emotion categorisation was significantly related to threat appraisals ($\chi^2_{df=1} = 4.85$, $p = .028$). For every point increase in threat appraisal levels, the odds of being in the EE category increased by 1.07 (95% CI = 1.01-1.15; Table 11).

Table 11: Binary Logistic Regression Analyses Predicting the Odds of Scoring High on Expressed Emotion based on Levels of Threat Appraisals.

95% CI for Odds Ratio				
Predictor	B (SE)	Lower	e^{β} (odds ratio)	Upper
Constant	-3.09 (2.23)			
Threat Appraisals	0.71* (0.04)	1.01	1.07	1.15

Note: Pseudo $R^2 = 0.21$ (Nagelkerke). Model $\chi^2(1) = 4.85$, $p = .028$. * $p < .05$.

Expressed emotion categorisation was significantly related to parental affective disturbance ($\chi^2_{df=1} = 9.53, p = .002$). For every point increase in parents' distress levels, the odds of being in the EE category increased by 1.24 (95% CI = 1.04-1.46; Table 12).

Table 12: Binary Logistic Regression Analyses Predicting the Odds of Scoring High on Expressed Emotion based on Levels of Parental Affective Disturbance.

Predictor	95% CI for Odds Ratio			
	B (SE)	Lower	e^b (odds ratio)	Upper
Constant	-1.40 (1.05)			
Affective Disturbance	0.21** (0.09)	1.04	1.24	1.46

Note: Pseudo $R^2 = 0.38$ (Nagelkerke). Model $\chi^2(1) = 9.53, p = .002$. * $p < .01$.

Expressed emotion categorisation was not significantly related to avoidant coping in parents ($\chi^2_{df=1} = 1.48, p = .224, ns$), nor to parents' social support availability ($\chi^2_{df=1} = 2.83, p = .093, ns$; see Appendix 13 for corresponding tables).

Both significant predictors of EE categorisation (threat appraisals and parental affective disturbance) were subsequently entered into a regression model predicting EE categorisation, using a forward conditional stepwise technique. Only parental affective disturbance remained as a significant predictor in the final model, and therefore the results reflect those outlined in Table 12.

Hypothesis Three

Increased child difficulties will be associated with increased parent affective disturbance, more threatening appraisals, less adaptive coping, lower levels of available social support, and greater likelihood of high EE in the parent-child relationship.

Four measures of child difficulties were gathered; two measures of PLE severity (parent- and child- reported) and two measures of emotional and behavioural difficulties (parent- and child-reported; SDQ). Increased child-reported emotional and behavioural difficulties were associated with increased child-reported PLE severity, and with increased parent-reported emotional and behavioural difficulties ($r_s [39] = .34, p = .034$; $r_s [39] = .49, p = .002$, respectively). Increased parent-reported PLE severity was associated with increased child-reported PLE severity and increased child-reported emotional and behavioural difficulties ($r_s [40] = .43, p = .006$ $r_s [40] = .42, p = .006$; respectively).

Child-reported difficulties were not generally related to parent psychosocial variables; only increased parent self-blame was significantly associated with increased child-reported PLE severity ($r_s [41] = .48, p = .002$). No other significant associations were found between child-reported PLE severity and parent psychosocial variables, or between child-reported emotional and behavioural difficulties and parent psychosocial variables.

Parent-reported PLE severity was not significantly associated with parent psychosocial variables. However, increased parent-reported emotional and behavioural difficulties were significantly associated with increased parental affective disturbance (anxiety and depression; $r_s [42] = .50, p = .001$; $r_s [42] = .52, p < .001$, respectively), with increased avoidant coping ($r_s [42] = .55, p < .001$), and with increased threat appraisals ($r_s [42] = .49, p = .001$). Spearman's correlations between child difficulties and parent psychosocial variables can be found in Table 13.

Biserial rank correlations did not find a significant relationship between parent- or child-reported PLE severity and EE categorisation ($r [33] = .15, p = .411, ns$; $r [34] = .07, p = .710, ns$), nor between parent- or child-reported emotional and behavioural difficulties and EE categorisation ($r [33] = .33, p = .059, ns$; $r [34] = .30, p = .081, ns$).

Table 13: Spearman's Correlations between Child Difficulties and Parent Psychosocial variables.

	Child-reported PLE Severity	Child-reported Difficulties (SDQ)	Parent-reported PLE severity	Parent-reported Difficulties (SDQ)
Child-reported PLE	-	.34*	.43**	.05
Child-reported SDQ		-	.42**	.49**
Parent-reported PLE severity			-	.13
Parent-reported SDQ				-
Parent Anxiety	.02	.15	-.07	.50**
Parent Depression	.05	.11	.06	.52**
Avoidant Coping	.07	.07	.03	.55**
Self-Blame Coping	.48**	.25	.08	.25
Threat Appraisals	-.01	.30	.12	.49**
Social Support Availability	-.04	.21	.15	-.04

PLE= Psychotic Like Experiences; *SDQ*= Strengths and Difficulties Questionnaire; * $p < .05$; ** $p < .01$, two-tailed.

Parent psychosocial variables were regressed on to the parent-reported measure of child emotional and behavioural difficulties. Only those parent psychosocial variables that were significantly correlated with child difficulties, (anxiety, depression, total threat appraisals and avoidant coping), were included in the regression model. Together, the variables accounted for 45.9% of the variance in parent-reported child difficulties ($F(4,37) = 7.83, p < .001$). Avoidant Coping was the only significant predictor, uniquely accounting for 10.2% of the variance ($\beta = .36, p = .012$; Table 14).

Table 14: Linear Regression Predicting Child Emotional and Behavioural Difficulties.

Predictor Variable	R^2	sr^2	$St\beta$
	.46		
Parent Anxiety		.01	.04
Parent Depression		.06	.31
Avoidant Coping		.10	.36**
Threat Appraisals		.02	.19

** $p < .01$.

Discussion

“All I want for her is to make something of her life, that’s it. Is that too much to ask? I don’t know! But to her it is. I mean, what every mother wants is the best for their child, isn’t it? I would just love her to understand, and to know how much, how much I just love her, and just want the best for her....”

“I just feel like I missed something along the way...is it because of me why he has all these problems?”

Quotes from participants

This discussion will initially characterise the sample. Difficulties experienced by parents and children are illustrated by considering parents’ mood and well-being, and children’s PLEs, emotional and behavioural problems. I will then discuss possible explanations for discrepancies between parent and child reports of children’s difficulties. I will also outline parents’ levels of social support, EE, coping and appraisals. Subsequently, I will discuss how the current results support the proposed hypotheses, and the overall model. Furthermore, I will describe potential mechanisms involved in the observed relationships and how these findings fit with the existing literature. I will reflect on the limitations of the study and how future developments in the field could further our understanding of the caregiving relationships in families of children with PLEs, emotional and behavioural difficulties. I will consider how the observed findings may impact on clinical practice in CAMHS settings. The discussion concludes with a summation of how this research fits with the broader clinical care of children and their families in mental health services.

This study examined relationships between parental threat appraisals, coping strategies, affective disturbance, social support and levels of EE in the parent-child dyad. The Cognitive Model of Caregiving suggests that parent psychosocial variables would predict EE in the parent-child relationship (Kuipers *et al.*, 2010). Hypotheses one and two investigated subsections of this model. **Hypothesis one** predicted a significant positive association between high EE parent-child dyads and levels of anxiety and depression. In line with this prediction increased parent depression and anxiety predicted high EE in the parent-child relationship. **Hypothesis two** predicted that significant associations would be found between increased parent affective disturbance and (i) higher levels of parents’ threat appraisals, (ii) increased use of less adaptive coping strategies and (iii) lower levels of social support. Results supported this hypothesis; increased threat appraisals, less adaptive coping and lower social support

were all associated with increased parent depression and/or anxiety. Threatening appraisals of the problem was the only measure that significantly predicted parents' affective disturbance. Subsequent exploratory regression analyses examined relationships predicted by the overall model, whereby parent affective disturbance, threat appraisals, coping strategies and social support were hypothesized to predict EE. In line with predictions, parental affective disturbance best predicted EE in the parent-child relationship. Threat appraisals also predicted EE, however the contribution of threat appraisals to the prediction of EE was negated when affective disturbance was added to the model. **Hypothesis three** predicted that increased child difficulties would be associated with increased affective disturbance, more threatening problem appraisals, less adaptive coping, lower levels of social support and greater likelihood of high EE in the parent-child relationship. This hypothesis was partially supported: parents' reports of children's emotional and behavioural difficulties were associated with increased parental anxiety and depression, avoidant coping and threat appraisals, but not levels of social support. Avoidant coping was found to predict parent-reported child emotional and behavioural difficulties. Due to the correlational nature of the data, causal relationships cannot be definitively established; however, hypothesised causal mechanisms are supported and these are discussed and considered.

Participants

The majority of caregivers were the mothers of the referred child, as is typical in research in this population (e.g. Wilkinson *et al.*, 2012; Triantafyllou *et al.*, 2012). The ethnic breakdown of the group was predominantly white British/Irish and Black or Black British, reflecting the demographic of the South London boroughs where recruitment took place. Three-quarters of caregivers had experience of having another family member with a mental health difficulty, which may have increased their knowledge and motivation to seek out services, as well as their prior beliefs about the causes and consequences of mental health difficulties.

Depression, Anxiety and Well-being of Carers

Parents' median well-being score was low; ninety per cent of adults in the UK have an equivalent or better level of well-being (Bryson *et al.*, 2012). Brannan and colleagues (1997; 2001) suggest that the subjective impact of caring manifests in parents' own mood problems. Forty-three per cent of parents in the current sample reached the threshold for clinical depression, and more than two-thirds met criteria for clinical anxiety. These results are similar to other studies of parents of children with emotional and behavioural difficulties (Hutchings *et al.*, 2011; Tan & Rey, 2011; Wilkinson *et al.*, 2012), and also reflect findings across other caregiving relationships (Cochrane *et al.*, 1997). Almost identical levels of affective disturbance

have been reported for parents of children with emotional and behavioural difficulties in a community sample (Green *et al.*, 2005).

Child Emotional and Behavioural Difficulties

Average levels of child emotional and behavioural difficulties were elevated in both parent- and self- reports. While parents reported average difficulties in the 'high' range, average child-reported difficulties were in the 'slightly raised' range (Goodman, 1997). Both child- and parent- reported difficulties were likely to reflect clinically significant problems. This finding was expected, given that participants were on the waitlist for CAMHS; they were likely to have been referred due to the presence of emotional or behavioural problems.

PLEs were frequently reported in this sample. The majority of children reported having a PLE in the past year, most within the last two weeks. PLEs are associated with a range of other emotional, social and behavioural difficulties in community samples (Laurens *et al.*, 2007; 2011), potentially resulting from shared risk, neurodevelopmental, genetic or neurobiological factors (Bartels-Venthuis *et al.*, 2011; Alemany *et al.*, 2011; Jacobson *et al.*, 2010). PLEs are also common in those seeking help from mental health services, who do not present with a psychotic disorder. Yung *et al.* (2006) found that almost all of the non-psychotic help-seekers they sampled endorsed the presence of a PLE. In addition, PLE rates have been found to be higher when assessed by self-report questionnaires rather than clinical interviews (van Os *et al.*, 2009), and higher for children than adolescents (Dhossche, *et al.*, 2002). High levels of PLEs were therefore expected in the young, help-seeking sample of children with emotional and behavioural difficulties, particularly where self-report measures were employed.

In line with previous studies (Laurens *et al.*, 2007; 2011), the majority of children reporting PLEs were not distressed or experiencing any other adverse impact of them. PLEs may even be beneficial in some cases; imaginary friends have been found to provide support and companionship in children (Majors, 2013). One third of children did experience impairment and distress related to their PLEs, however. PLE associated distress and impairment was higher than that reported for community samples. This suggests that children experiencing PLE-related distress or impairment are more likely to present to mental health services. As reported by Yung *et al.* (2006), PLEs associated with Magical Thinking (telepathic communication, having special powers, being sent special messages), were associated with the low levels of distress and impact, although they were frequently reported.

Discrepancies in Parent- and Child- Reports

Many parents appeared unaware of their child's PLE, but did report high levels of difficulty with emotional and behavioural functioning. Parent-reported SDQ mean scores were higher

than those self-reported by children, contrary to previous findings that adolescents report significantly more problem behaviours than their parents (Bird, Gould, & Staghezza, 1992). The mean child-reported PLE severity score was higher than parent-reported PLE scores, however. Parents' reports of difficulties on the SDQ include behavioural and social problems that they are dealing with on a daily basis. In contrast, PLEs may not be observable to parents, and thus underestimated in parent reports. Research has suggested that while externalising problems may be easily identified by parents, internalising problems may be poorly recognised (Bird, Gould, & Staghezza, 1992; Sourander, Helstelä, & Helenius, 1999).

Another possible explanation is that parents' own levels of stress and strain may magnify their perceptions of their child's difficulties. A bi-directional relationship between parent and child influences has been proposed; child difficulties are likely to increase parenting stress, and increased parenting stress may result in parents perceptions of their child's difficulties being magnified (Deater-Deckard, 2004).

Parents may also have been motivated to emphasise their child's difficulties in the hope that it would improve their access to CAMHS.

Parent Social Support

Parents reported having between two and three people available to them in their social support network. This is comparable to the levels of social support available to caregivers of patients with psychosis, who have an average of just under three people available to them in their social support network (Gouva *et al.*, 2012), but lower than findings in a non-clinical population (more than four people, on average; Sarason, Levine, Basham, & Sarason, 1983). Parents reported high levels of satisfaction with their social support network. They were more satisfied than caregivers of patients with psychosis (Gouva *et al.*, 2012), but less satisfied than a non-clinical population (Sarason *et al.*, 1983). The availability of parents' social support may have been reduced due to the stigma associated with mental health difficulties, or parents feeling blamed for their child's difficulties and behavioural problems. Parents may feel unable to talk to family and friends, or may restrict their social activities due to their child's difficulties, leaving them feeling isolated. Lefley (1989) found that the stigma associated with a child's mental health difficulties often leads to social isolation for parents.

Expressed Emotion

The majority of caregivers (80.0%) were classified as high EE. Previous studies of children with PLEs have also found elevated levels of EE (O'Brien *et al.*, 2006; Polanczyk *et al.*, 2010). The percentage of parent-child dyads rated as high EE in the current sample was notably high however, exceeding previous PLE studies. Levels of EE found here are comparable to those

found by Calam & Peters (2006), in a community sample of mothers with children with behavioural problems. They found that 90.0% of their sample were categorised as high EE, using the FMSS. In the current sample, as with Calam and Peters' (2006) cohort, parents were likely to have been keen to stress the extent of the difficulties that they were experiencing with their children, and often made exceptionally negative comments about them.

High levels of EE may represent a manifestation of parents' worry surrounding the initial identification of mental health difficulties. In particular, criticism has been found to be associated with externalising problems, and may reflect parents' attempts to influence their child's behaviour through critical feedback (Stubbe *et al.*, 1993; McNab *et al.*, 2007). EOI has been associated with emotional difficulties, and may reflect parents' concern for a child with internalising problems (Stubbe *et al.*, 1993). The majority of parents in the high EE category (26/28) displayed critical or borderline critical features. This may indicate high levels of negative parenting behaviours in this group (Hastings & Lloyd, 2007; McCarthy *et al.*, 2004). How parents choose to talk about their child in the FMSS has been suggested to indicate how they interact with their child on a daily basis (Chambless, Bryan, Aiken, Steketee & Hooley, 1999).

Parent Coping

Average levels of avoidant coping in parents of CAMHS referred children were equivalent to research with carers of adults with psychosis (Onwumere *et al.*, 2011). Self-blame was the most frequently used coping strategy. Previous studies have found high levels of self-blame in parents of children with disabilities (Nixon, & Singer, 2002). Wortman (1976) has suggested that self-blame may provide a coping strategy when it is used as an 'explanation', that provides some perceived control over the future occurrence of a negative event (e.g. "It was my fault, but I won't let it happen again"). Parents' self-blaming behaviour may not have increased their sense of control in the current sample however; future research is necessary to further examine parents' self-blaming beliefs. In addition, parents reported the frequent use of support-seeking and active coping; strategies that they are likely to have used in the past, in order to reach the CAMHS waitlist.

Parent Appraisals

Parents' mean level of concern about their child was close to the maximum for the subscale. As previously discussed, children seeking help differ from adult help-seekers because they rarely refer themselves for treatment. High levels of parental concern may have prompted the CAMHS referral and thus may be inflated in the current sample, as compared to a community sample. Parents also reported being highly emotionally affected by their child's problems. The high emotional representation could reflect high parent burden, a factor shown to be a major

reason for mental health service use (Angold *et al.*, 1998). When asked to list causes of their child's problems, the majority of parents (61.2%) cited reasons related to parenting. Parent-related causes ranged from parents behaviours during pregnancy (e.g. alcohol/drugs use or maternal depression), caregiving (poor attachment between child and parent, inconsistent caregivers), parent discipline, parental mental health and relationship between parents (divorce and conflict). Such parent-related causal appraisals are understood in the context of the high levels of parental self-blame.

Hypothesis One: Parent Mood and Expressed Emotion

The principal aim of the study was to examine whether parent mood accounted for variance in EE. Results show that parents with increased levels of anxiety and depression were also more likely to report high EE in the parent-child dyad. Both depression and anxiety predicted EE. Estimates of the variance explained by both mood measures indicated that depression predicted more of the variance in EE than anxiety (26.0% versus 38.0%). It is likely that much of the variance explained by depression and anxiety is shared, due to the high correlations between both mood measures, and a similarity in the constructs that they measure. It still appears that parental mood accounts for a substantial amount of the variance in EE, however. This result is consistent with findings by Bolton *et al.* (2003), who found maternal mood to be a predictor of maternal criticism. Irritability associated with depression may increase parents' use of criticism. The experience of having a child with emotional and behavioural difficulties is a risk factor for parental affective disturbance (Wilkinson *et al.*, 2012). Direct observations of mother-child interactions have found that depressed mothers display more sad and irritable affect than non-depressed mothers (Cohn, Campbell, Matias & Hopkins, 1990). Depressed mothers have also been shown to engage in more negative, angry, intrusive, hostile and conflictual behaviour with their children (Goodman, Adamson, Riniti & Cole, 1994; Hammen, 1991).

Parent and child factors are likely to interact in the development and maintenance of high EE (Goldberg-Arnold *et al.*, 1999). For example, over-protective and intrusive concern towards the child may be motivated by parents' anxiety, through a belief that self-sacrificing or over-protecting behaviour can ameliorate their child's symptoms, or that criticism can motivate their child to change their symptoms. Consequent high EE interactions may, in turn, increase the likelihood that the child experiences more severe problems, perpetuating an escalating cycle of high EE and parental affective disturbance. Hahlweg *et al.* (1989) found that high EE relatives of those recently diagnosed with psychosis showed extreme negative escalation patterns in their interactions with patients.

Hypothesis Two: Psychosocial Variables and Parent Mood

Consistent with expectations, parents who reported increased levels of depression and anxiety also appraised their child's problems as more threatening, used less adaptive coping strategies, and had less available social support. Parents' overall threat appraisals predicted parent anxiety and depression, uniquely explaining 14.1% and 15.4% of the variance in anxiety and depression, respectively. This supports relationships in the overall model, where caregiver appraisals have a direct influence on caregiver cognitive and affective changes (Kuipers *et al.*, 2010). Results are also in line with Dix and Lochman's (1990) 'Cognitive-emotional Model' of parenting. They found that attributions mediated mothers' reactions to their child with behavioural problems, through their effects on parents' affect.

Parent Mood and Appraisals of Threat

Parent anxiety and depression was significantly associated with increased appraisals of threat regarding the child's difficulties. This included parents' perceptions of their child's problems as increasingly concerning, emotionally impacting and chronic, with more consequences for their child and for themselves, poor understanding of the problems, weaker beliefs in treatment and personal control, but stronger beliefs that the child could control their own symptoms. The association between parents' threat appraisals and affective disturbance are in line with findings for relatives of adults with psychosis (Fortune *et al.*, 2005).

Associations between parent mood and specific threat appraisals (chronicity, controllability and child consequences) were also examined. In line with reports by Weiner (1985), a trend in the results indicated that parents' appraisals of the consequences for the child, was associated with increased parent anxiety. Furthermore, a trend in the results suggested that parent appraisals of child's problems as controllable by the child, related to increased parent anxiety and depression. Parent appraisals of their child's problem as long lasting were associated with increased parent depression and anxiety.

Attributing an individual's problems to internal and long lasting causes has previously been associated with negative caregiver mood (Dix & Grusec, 1985; Onwumere *et al.*, 2008). Contrary to the current trend showing a positive association between child control and parent affective disturbance, Fortune *et al.* (2005) found that carers who held a stronger belief that their relative could exert personal control over their symptoms had *less* distress. The difference in findings may reflect the fact that relatives in the previous study were engaged with services and participants were attending carer information and support groups. Carers' beliefs that their relative could control their symptoms might have reflected their experience of effective treatment, and the hope that patients could make treatment gains by exerting control. In contrast, the current participants were awaiting service input. Parents' perceptions

that children could control their symptoms may have only caused increased frustration, because problems are seen as volitional. They may also be more likely to employ criticism in an attempt to motivate their child to change (e.g. McNab *et al.*, 2007), resulting in a poorer parent-child relationship. This highlights the important role played by carers' relationship with services.

Worry and catastrophic cognitions may also mediate the relationship between appraisals and parent mood; parents who believe that their child's problems are chronic and will have major consequences are likely to experience increased worry, which may negatively impact on their mood (Triantafyllou, *et al.*, 2012). Reports of increased threat appraisals may also reflect a general cognitive bias of parents with mood disorders, as depressed adults have been shown to make more negative, internal, stable and global attributions in general (Goodman & Gotlib, 1999).

Parent Mood and Coping

A trend in the results suggests that parent avoidant coping may be associated with levels of parent anxiety. This is in line with findings for adults with anxiety, who report high levels of avoidant coping (Blalock & Joiner, 2000), and the central role of avoidance in many cognitive behavioural models of anxiety disorders. Within the Cognitive Model of Stress and Coping (Lazarus & Folkman, 1984), avoidant coping may reflect the parent's negative appraisal of their ability to manage a stressful situation (i.e. the problem is seen as exceeding their resources). This can result in increased stress and anxiety. Furthermore, parents with mood disorders are likely to have low self-efficacy and may feel unable to control the situation (Goodman & Gotlib, 1999). Kuipers *et al.*, (2006) found low self-esteem was related to high EE in family members of patients with psychosis. An appraisal of a situation as personally uncontrollable is related to the use of avoidant coping (Carver *et al.*, 1989; Folkman & Lazarus, 1980, 1985). This pattern of relationships, whereby parents' appraisals influence their subsequent use of coping strategies and mood, is consistent with the Cognitive Model of Caregiving (Kuipers *et al.*, 2010). Cotton *et al.* (2013) suggest that interventions facilitating the use of adaptive problem solving and positive re-appraisal will promote carer coping and reduce psychological distress.

Inconsistent with expectations was the finding that self-blame coping was not associated with either parent anxiety or depression. It appears that self-blame was high for all parents, regardless of mood, indicating the propensity of parents to view themselves as a factor in their child's difficulties. Previous research had shown that depressed mothers were more likely to endorse negative views of themselves as parents (Goodman, Sewell, Cooley & Leavitt, 1993), and see themselves as the cause of their children's problems (White & Barrowclough, 2011). In addition, Meyer (2001) notes that there may be some conceptual overlap between self-blame

coping strategies and depression, which could result in a high correlation between these variables, however this was not found in the current study. Previous research has found an association between EE and self-blame in relatives of people with psychosis (Wasserman *et al.*, 2012; Peterson & Docherty, 2004), and an association between EOI and self-blame coping for parents of children with problem behaviours (Bolton *et al.*, 2003). High EE dyads in the current sample were predominately categorised on the presence of criticism, rather than high EOI, and this may have impacted on the failure to find support for this hypothesis.

Parent Mood and Social Support

Consistent with expectations, less availability of social support was associated with increased parental depression. This negative relationship between available social support and mood is well established (Taylor, 2011; Koizumi *et al.*, 2005). Within this cross-sectional data it is not possible to infer causal relationships. The tendency for parents to be isolated as a result of their child's difficulties has been previously discussed (p.58), however parents may have low levels social support that pre-date their child's difficulties. These parents may find it more difficult to cope with the stress of the onset of their child's problems, leading to affective disturbance. Parents' perceptions that they have many people upon whom they can depend, can buffer against the stress of their child's difficulties (Brannan & Heflinger, 2001; Breevaart & Bakker, 2011). Parents do not need to actively use their social support; they can be bolstered against affective disturbance by merely feeling that the support is there if it is needed. Alternatively, poor social support may be related to parents' mood independent of their child's difficulties; individuals have been found to withdraw from interaction with depressed persons (Goodman & Gotlib, 1999).

Higher levels of social support are associated with adaptive coping and less burden in carers of people with psychosis (Magliano *et al.*, 2003; Boydell *et al.*, 2013). Although not examined in the current study, the role of coping may help to understand the association between depression and social support, in line with the overall Cognitive Model of Caregiving. This relationship warrants future examination. Parents have been found to be more likely to use adaptive coping strategies when they believe that they have supportive others in their network (McDonald *et al.*, 1997; 1999). For example, the availability of supportive others may facilitate the use of emotional and instrumental support strategies. Within the Cognitive Model of Stress and Coping (Lazarus & Folkman, 1984), believing oneself to have a good social support may influence the parent's positive appraisal of their ability to manage a stressful situation (i.e. they see themselves as having the resources to cope with the problem), resulting in less distress.

Psychosocial Predictors of the Parent-child Relationship

These results support the hypothesised relationships in the Cognitive Model of Caregiving. Kuipers *et al.* (2010) proposes that changes in caregiver affect mediate the relationship between caregiver appraisals and the carer's relationship with the care recipient. The current study found that: (i) parent appraisals predicted parent mood, (ii) parent mood predicted EE in the parent-child relationship, and (iii) parent mood was a better predictor of EE than appraisals. Unfortunately the small sample size limits the ability to test whether a mediational relationship exists. Although parent coping strategies and social support did not predict EE in the parent-child relationship, with only seven events in the low EE category, a 'fringelier'¹ in the data could have a disproportionately strong influence on results (Osborne & Overbay, 2004).

These results replicate previous findings by Bolton *et al.* (2003) in mothers of children with problem behaviour. If mood does indeed mediate the relationship between appraisals and EE in the relationship, it suggests that cognitive interventions to target parents' attributions about their child's difficulties could have benefits on both parent mood and on the parent-child relationship.

Hypothesis Three: Parent Psychosocial Predictors of Child Difficulties

In line with expectation, children with increased self-reported emotional and behavioural difficulties (as measured by the SDQ) were more likely to self-report increased PLE severity, similar to findings in community studies (Laurens *et al.* 2007; 2011; Kelleher *et al.*, 2012; Polanczyk *et al.*, 2010). As further hypothesised, parent-reported child difficulties were related to parent anxiety and depression. These results were consistent with previous findings (e.g. Tan & Rey, 2005). Increased child difficulties may cause parents to experience increased affective disturbance. Alternatively, parents that appraise their child's difficulties more negatively may be more likely to appraise their own difficulties more negatively, directly resulting in increased mood difficulties, and/or making it more likely that parents will self-report a mood difficulty due to their negative bias. Consistent with the cognitive perspective on depression, researchers have argued that depressed mothers' perceptions of their children's behaviours are negatively distorted (e.g. Friedlander, Weiss & Traylor, 1986). However, others propose that depressed mothers are accurately reporting their children's behaviour (Conrad & Hammen, 1989; Richters & Pelligrini, 1989). It is not clear if the current results reflect the inaccuracy of parent reports (i.e. a 'depression distortion'), or the association between difficult child behaviours and depressed mothers more negative response style. Parental burden is a

¹ These are data that aren't too far from the standard deviations, but have a strong influence on parameter estimate (Wainer, 1976).

major reason for child mental health service use, and this burden is predicted by child symptomatology and parent mental health problems (Angold *et al.*, 1998). It is likely that the high levels of parent depression and child difficulties indicate high levels of parent burden in the current sample of help-seekers.

Goodman and Gotlib (1999) highlight that depressed parents are characterised by negative perceptions of their children, and difficulties interacting with their children. The relationship between parents' depression and children's problem behaviours may be mediated by negative interactions between the parent and child, indicated by high EE. In support of this hypothesis, Boyle and Pickles (1997) report that both maternal depression and the associated negative impact on family relationships may contribute to mothers negatively biased reports. Bolton *et al.* (2003) also found support for the hypothesis that criticism might act as a mediator between parent mood and child difficulties. Future research with bigger samples is warranted, to test this potential mediational relationship.

Levels of EE were not associated with the presence of PLEs, contrary to previous findings among children with PLEs (Polanczyk *et al.*, 2010). Although EE is raised in PLE, prodromal and at-risk populations (Meneghelli *et al.*, 2011; Hooley & Richters, 1995; Schlosser *et al.*, 2010), rates of high EE can be lower than for those with a diagnosed psychotic illness (McFarlane & Cook, 2007; O'Brien *et al.*, 2006). The effect size for the relationship between EE and PLEs declines with decreasing age and problem severity. This is a small sample of young children, with problems of relative low severity; therefore the likelihood of finding a significant association between EE and PLEs was reduced.

Higher parent-reported child difficulties were associated with increased parent threat appraisals. It is understandable that parents' who perceive their child's emotional and behavioural symptoms as severe would also see the problems as more threatening. Higher parent-reported child difficulties were also associated with increased avoidant coping. Parents may have been more motivated to use disengagement, denial or substance-use (i.e. avoidance strategies) to cope with feelings of being overwhelmed, when they perceived their child's difficulties as more severe. Avoidance may be a factor in the development and maintenance of parent mood difficulties and high EE relationships; those children with more severe difficulties may be more at risk, given the higher propensity for parents to use avoidant coping.

Limitations

The current study has a number of limitations. Results are based on a small, cross-sectional sample, and therefore the causal direction of relationships cannot be directly tested. The hypothesised mechanisms accounting for how parent appraisals, mood, social support, coping

and EE are related is supported by the current findings, but not conclusively demonstrated. Prospective or experimental designs are required to determine the direction of the relationship between EE in the parent-child relationship and parent psychosocial variables. Suggestions for future research to overcome this limitation will be discussed (p.68).

The order of administration of the measures is a limitation that may have influenced parents' responses on the FMSS, inflating levels of high EE. As some parents can find the FMSS an unusual task, it was typically administered in the latter stages of the assessment, when some rapport had been established with the parent. Parents initially answered closed questions related to their child's difficulties and their own difficulties in depth. Caregiver burden has previously been associated with levels of high EE (Raune *et al.*, 2004). Administration of the FMSS following this comprehensive battery of structured questionnaires might have primed parents to consider their caregiving burden, increasing their propensity to express high EE in the subsequent FMSS. Equally, however, commencing the start of the assessments with the FMSS may have influenced the parent recall of troubling events that may have impact on their affect measures and reports of the difficulties encountered by their child. Future research should consider how to counterbalance the administration of measures, while continuing to establish sufficient parent rapport.

The sampling of participants on a waitlist has implications for both the generalisability of the model, and interpretation of the results. The Cognitive Model of Caregiving includes a consideration of caregivers' relationship with services. Family burden is increased by a lack of appropriate services (Lefley, 1997). Parents' reports of their own difficulties, and their child's difficulties, may have been influenced by their waitlist status. A lack of access to services may have increased the burden for parents, and their desire to communicate their need for service input. In addition, the sample was drawn from an area of high levels of economic and social deprivation, which may have implications for the generalisability of results. Socio-economic status was not measured. Its inclusion could help to identify groups who are more likely to have elevated levels of EE. Calam and Peters (2006) suggest that it may be necessary to employ variable thresholds for the identification of EE within different populations.

Clinical Implications

The current findings have important clinical implications regarding the assessment of PLEs in CAMHS settings, and the consideration of parent factors in the assessment and treatment of child difficulties. A significant minority of children reported distress and impairment related to their PLE. This finding supports the proposition that PLEs should be carefully assessed in CAMHS settings as they may indicate that a child is at risk for emotional and behavioural problems that require a more comprehensive care plan (Kelleher *et al.*, 2012). Helping families

to understand and cope better with PLEs earlier in childhood may help to minimise the impact of the PLE symptoms, distress and negative sequelae that may be associated with high EE interactions. Where PLEs do not discontinue they may be associated with a range of increasingly severe emotional and behavioural problems (Kelleher *et al.*, 2012). Structured diagnostic interviews have been found to be more predictive and valid than parent-reported behavioural problems when identifying children at high-risk for developing a psychiatric disorder (Wassenberg, Max, Keole, & Firme 2004; Reitman, Hummel, Franz & Gross 1998). While observer-reports can be a useful adjunct to assessment, the finding that many parents are unaware of their child's distressing PLEs highlights the importance of in-depth clinical interviews with the child. Clinicians should be trained in asking relevant and probing questions related to PLEs, as well as the ability to normalise the experience for both the parent and child. For many children PLEs will be developmentally appropriate. Where clinicians identify the presence of transient or attenuated psychotic symptoms that are distressing or impairing for the child, both individual and family interventions should be offered (NICE, 2012). In addition, an awareness of PLEs can inform work with other agencies, for example schools and clubs, in promoting the good mental health and well-being of children. The efficacy of interventions for children with PLEs is currently being evaluated in the larger CUEs trial. Beneficial results have already been seen in the results of a case series (Maddox *et al.*, 2012).

Parent factors are an important consideration during assessment and intervention for children with emotional and behavioural problems. High EE is not only related to parent affective disturbance, but the parent-child relationship, and in particular the presence of criticism, is related to increased child problems (Baker *et al.*, 2000; McCarthy & Weisz, 2002; Bolton *et al.*, 2003). High EE has been cited as risk factor for poorer long-term outcomes for children with psychological difficulties, although the mechanisms through which this happens are unclear (Wearden, *et al.*, 2000; Weintraub & Wamboldt, 1996). Peris and Baker, (2000) found that high EE predicted children's problem behaviour four years later, suggesting a causative rather than consequential role in the development of child problems. Alternately, EE may act as a maintaining or exacerbating factor for child difficulties (Bolton *et al.*, 2003). Targeting parent mood, coping, social support and appraisals may be routes to reducing parent burden and critical parent-child interactions.

Purely behavioural models of parenting interventions (e.g. parent skills training) can overlook parent cognitive and emotional factors. Interventions that address parent emotional and cognitive influences (e.g. parent CBT or psycho-education) may improve parents' affective disturbance, the parent-child relationship, and child outcomes. For example, in the context of high levels of parent self-blame, psychoeducation may be beneficial to help parents

understand the biopsychosocial causes of children's difficulties. Children may be less likely to feel criticised in their daily interactions with their parents, due to a reduction of EE in the parent-child dyad (Chambless *et al.*, 1999). Children may also be less likely to learn maladaptive cognitive styles from parents where parent emotions and cognitive factors are targeted (Moore *et al.*, 2004; Whaley *et al.*, 1999; Goodman & Gotlib, 1999). And, in turn, reduced child problems may decrease parents' risk for anxiety and depression (Wilkinson *et al.*, 2012).

Whether parent factors have a causal relationship with child difficulties, or whether child difficulties cause increased parent difficulties remains unresolved. Regardless of the precipitant, both parent and child factors can maintain difficulties. High EE interactions are one way this cycle may be perpetuated. Intervening at a parent level, as well as with the child, may benefit the effectiveness of treatment and have positive implications for both child and parent. This is supported by findings that treating parental affective disturbance results in improved child symptoms (Gunlicks & Weisman, 2008; Weissman *et al.*, 2006; Hutchings, *et al.*, 2012).

Future Research

A review of the role of fathers in the development and treatment of child emotional disorders found that fathers have a significant and distinctive role to play in children's mental health (Bögels & Phares, 2008). As few fathers participated, a comparison of mothers' and fathers' responses was unavailable; however an examination of paternal and maternal perspectives is important for future studies.

The proposed model assumes that the way in which parents speak about their child in the FMSS reflects their interactions with the child on a day-to-day basis. This assumption is also reflected in clinical settings; Calam *et al.* (2002) found that parent criticism (as measured using the CFI) was associated with independent ratings of perceived parent maltreatment potential by clinicians. Support for the association between daily interactions and EE ratings is supported in the literature. McCarthy and colleagues (2004) found that criticism, but not EOI, was related to observed parent-child interactions. It should be noted that this is not necessarily always the case however (Wamboldt, Wamboldt, Gavin, Roesler & Burgman, 1995), and future research is needed to test the extent to which EE relates to actual parenting behaviour and aspects of the parent-child relationship.

The current results, and evidence from previous literature, indicates that parental appraisals of the problem as threatening, parent mood and high EE are inter-related variables that have the potential to make a meaningful impact on our knowledge and treatment of parenting

problems and child difficulties. Prospective or experimental designs are required to determine the relationship between EE in the parent-child dyad and parent psychosocial aspects. The Cognitive Model of Caregiving proposes that cognitive and affective *changes* will occur as a result of caring (Kuipers *et al.*, 2010), however the current data do not exclude the possibility that parents had pre-existing affective disturbance. Pre-existing mood difficulties have been shown to increase parental burden of caregiving (Angold *et al.*, 1998). Causal relationships could be investigated through longitudinal, prospective designs in non-clinical samples. For example, prospective research designs are needed to test the impact of pre-existing parental affective disturbance on the subsequent development of child difficulties, parent parents' use of less adaptive coping responses, threatening problem appraisals and available social support.

Future research can also help to identify mediational relationships between parent and child factors. The mechanisms that link parent appraisals to affective disturbance, and those that link affective disturbance to EE, need to be explored. Future research can build upon the current results in contributing to the systematic evaluation of the potential benefit of combining parent affective and attributional approaches with behavioural interventions. Empirical evidence is needed to measure changes in parent mood, appraisals, coping and EE, before and after receiving interventions that combine cognitive and behavioural targets. Comparisons with control groups, and behavioural-only interventions, will help to further tease apart the specific contribution of adding affective and attributional aspects to parent treatment.

Conclusion

A recent statement from the Royal College of General Practitioners (GPs) advised that all carers should be routinely screened for signs of depression by their GP to ensure their health needs are not neglected ("Screen Carers", 2013). In support of this recommendation, this study found that parents of children referred to CAMHS had high levels of anxiety and depression. Parents' appraisals of their child's difficulties as threatening predicted the development of these parent mood problems. Parent mood problems may impact on the parent-child relationship; anxiety and depression predicted EE in parent-child dyads in the current study.

PLEs were found to be common and sometimes distressing among children awaiting CAMHS input. In many cases parents were unaware of the existence and severity of their child's PLE. Interventions for children with distressing PLEs, and their parents, can be undertaken to promote resilience, and to off-set a potential negative mental health trajectory for both parents and children. Controlled experimental designs can investigate the effectiveness of parent interventions in influencing parent outcomes and the parent-child relationship. In most

cases, PLEs constitute a normal part of development, are not distressing, and resolve naturally. Where PLEs *are* distressing for the child, targeted interventions to address PLE related distress and improve coping, may not only alleviate current difficulties, but also offset a later need for care. A recent review has recommended early intervention should focus on the broad syndrome of early mental distress (Fusar-Poli, Yung, McGorry & van Os, 2013). This may allow both broader outputs, as well as inputs, by including those with early, sub-threshold symptoms (McGorry, 2013). In many cases children will not go on to develop a severe mental health problem, however support and care for parents and children may still be beneficial; individuals identified at high-risk for psychosis, but who *did not* go on to develop a psychiatric disorder, showed reduced social and role functioning in a two year follow up study (Addington *et al.*, 2011). Linscott and van Os (2012) have recommended that a greater understanding of what it is that prevents some people from developing dysfunction, despite PLEs, may also offer intervention targets.

Increasingly, research has examined the trajectory of psychosis development, using first episode, prodromal and at-risk groups. There is growing evidence that models of psychosis may be applicable for these groups. Research is now further extending to children with PLEs, to examine how early in this trajectory we can meaningfully understand the risk factors associated with the later development of severe mental illness. The current study examined whether cognitive models of caregiving in psychosis could equally be applied early in this trajectory. While the Cognitive Model of Caregiving was not originally proposed for carers of children, many similar relationships seem to exist for carers of adults and children with mental health problems. The influence of parents' and adolescents' communications on each other is central to systemic models in psychology (e.g. Minuchin, 1977). Intervention in any one part of the family system has ripple effects throughout the entire system. Within health services the needs of parents should be considered in their own right, because interventions to reduce parental distress and improve parental coping are likely to benefit not only the parent, but also for the child, in both their current and future well-being.

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Appendices

Appendix 1: Ethical Approval

Appendix 2: Letter for prospective participants to be sent to parents of children referred to Tier 2 CAMHS, and placed on the waiting list

Institute of
Psychiatry

at The Maudsley

South London and Maudsley 
NHS Foundation Trust

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KING'S
College
LONDON
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Dear Parent/Carer,

We are writing to everybody who is referred to Child and Adolescent Mental Health Services to ask if they would like to take part in a research study. We are contacting everybody in this way to make sure we do not miss anybody out. It is entirely up to you whether you decide to take part, and this will not affect the care you receive from the service you have been referred to in any way.

With this letter, we have sent some information sheets that describe the study and what it will involve. There is a sheet for you, as parent or carer and a short sheet for your child, and a longer sheet for your child in case they would like to know more.

If you are not interested, or would prefer not to take part, please just ignore or destroy the letter and the sheets. If you would like to find out more about the study, or think you might like to take part, please contact us on [insert contact details].

A researcher from the study will try to call you in a week or so, to check if you have received the letter and whether you would like to find out more or to take part.

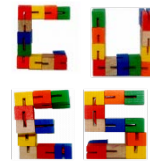
You do not have to speak to the researcher, and if you would prefer them not to call you, please let us know on [insert telephone number].

Thank-you for your time.

With best wishes,

[Insert researchers details]

Appendix 3: Information Sheet for Parents and Carers



Information Sheet for Parents/Carers Version 2 – 10/4/11

Title of study: Coping with Unusual Experiences (CUES)

We are inviting you and your child to take part in a research project.

You should only take part if you want to.

If you do not want to take part, this will not affect the usual care or services that you or your child receive in any way.

Before you decide whether you want to take part, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully.
One of our team will go through the information sheet with you and answer any questions you have. This should take about 15 minutes.
Talk to other people about the project if you want to.

- Part 1 tells you the purpose of this project and what will happen to you if you take part.
- Part 2 gives you more detailed information about how the project will be carried out.

Please ask us if there is anything that is not clear or if you would like more information.

Contact details: Nedah Hassanali (Research Worker), Claire Tobin (Clinical Psychologist in training, Jonathan Bradley (Clinical Psychologist in training). Department of Psychology, King's College London, Institute of Psychiatry, Denmark Hill, London, SE5 8AF. Tel no: 0207 848 5794/ 07427475940

Karen Bracegirdle (Research Therapist): South London and Maudsley NHS Foundation Trust, Southwark CAMHS, 1st Floor Mapother House, De Crespigny Park, London, SE5 8AZ. Tel no: 0203 228 7777/ 07427425411

REC Reference Number: R&D2011/028

You will be given a copy of this information sheet

Part 1

What is the purpose of the project? We are trying to find new ways to help children cope with unusual experiences, emotional problems and stress. We have put together a package of strategies, which we hope will be helpful. We talk young people through the package to help them learn new ways of coping with their problems. The package is based on talking therapies which have been shown to be helpful for both adults and children reporting anxiety or worries, low mood and unusual experiences. Some children have already completed the package, and they said they liked it and found it helpful. The next step is for more children to complete the package and for us to find out how they feel and how they are coping before and after completing the package, and to compare this to children who have not completed the package.

We also want to find out more about the causes of upsetting unusual experiences in young people, so we will be asking all the children who agree to take part in the study, and their parents or carers, to answer some questions about feelings and experiences, and complete some activities about everyday problems and situations. We will then compare a group of children with unusual experiences who feel upset to children who do not have these experiences.

What do you mean by ‘unusual experiences’? Lots of people have experiences which can seem unusual to others. For example, hearing voices that other people cannot hear, seeing, feeling or smelling things that other people cannot, or finding that things around them look somehow odd or different. These experiences are much more common than most people think and often do not cause any problems for the people experiencing them. They might even be enjoyable. However, sometimes these experiences can be upsetting or worrying to the person who has them, or can stop the person doing what they normally do. This in turn can interfere with school or work, friendships and family relationships. There are some strategies for dealing with both the experiences and the upset that can happen alongside them. The package is a collection of these strategies, and we would like to find out whether it helps young people to cope.

Why has my child been asked to take part? We are offering the package to children aged 8-14 who are seeking help from Child and Adolescent Mental Health Services. For the first part of this study, we are inviting all children in the service and their parents/carers to complete two questionnaires which ask about unusual experiences and feelings. This is to find out if the package will suit your child. Your child will need to be able to speak enough English to understand the package and the questionnaires. For the second part of the study, we will offer the package to children who report an unusual experience and feeling upset. We will also ask some children who do not report an unusual experience and feeling upset to complete some questionnaires and activities.

What will my child and I be asked to do?

Stage 1: If you and your child would like to take part in the study, you will first need to sign the form at the end of this sheet, to say that you are happy to go ahead. In the first stage of the study, your child will complete the two questionnaires to see if the package is suitable. These will take about 15 minutes to complete, in a short meeting with a research worker. If the package is suitable for your child, he or she will be invited to take part in the second stage of the study.

If the package is not suitable for your child (because he or she is not having unusual experiences or feeling upset), we will ask you and your child to complete some questionnaires about feelings and experiences, and complete some activities designed to show how people think about everyday problems and situations so we can find out more about what causes unusual experiences and upset. This will usually take two or three meetings or about two hours in total, with the research worker, and can be spaced over as many meetings as you like.

Stage 2: In the second stage of the study, half of the children taking part will be invited to complete the package immediately, and half will be asked to wait for 3 months before completing the package. This is so that we can see if adding the package is more helpful than just waiting for help from Child and Adolescent Mental Health Services.

To see if the package is more helpful than just waiting, it is important that the group of children who receive the package straight away and the group who have to wait for 3 months are as similar as possible. Whether your child receives the package straight away or after a wait will therefore be decided by chance (randomly), by a process a bit like tossing a coin. This will be carried out at a centre separate to the research team, who will not have any information about you or your child. You will not be able to choose which group you and your child are in, nor will any member of the team.

Completing the package will involve your child attending some meetings with a therapist. There will usually be around 9-12 meetings lasting about 45 minutes each, but we can arrange the number and length to suit your child. The meetings will usually take place weekly for between two to three months. They will be held at a location to suit you and your child. We will try hard to make appointment times convenient for you and your child. For example, wherever possible appointments will be made outside of school hours.

As a way of checking that the therapists and research workers are all working in the same way, and working with the package as well as possible, we would like to audiorecord the meetings. You and your child will be asked whether this is OK each time they meet with the therapist or researcher.

You and your child will be asked to complete some questionnaires and activities at the very start of the study, after completing the package or after the 3-month wait, and again after one month, so we can see if any positive changes last after the package has been completed. The questionnaires and activities are to see whether the package is helping your child or not. This usually takes two or three meetings with a researcher, or about two hours in total. Your child will also be asked how they found the package and any changes they would suggest for the future. We will also ask you for feedback on how you have found things while your child has been attending the meetings.

Your child will be given a £5 gift voucher as a thank-you for taking part in the project.

Will my and my child's taking part in the study be kept confidential? The information you and your child give us will usually be available only to the research team. However, the researcher will share with your clinical team any important information that is relevant to the care you receive, and will let the team and your GP know that you are taking part in the study, and will note down on the team's notes system that you are taking part in the study and when they meet with you. If you or child tell us anything about someone being hurt or not safe, we will have to tell other people who are there to help with these kinds of situations. More details are included in Part 2.

How will the information we give you be kept? All the answers you and your child give to the questionnaires and activities will be kept on paper and as an electronic file. The recordings will be kept as electronic files. They will be kept securely and anonymously and will be identified only by a number, not by your name. Your name will be kept separately, with the number, on paper, so that we can identify your questionnaires and recordings in the future if we need to (for example, if you decide you no longer want to be part of the study). We will only identify your questionnaires for a reason like this. Your details will be kept for up to 12 years, and then will be confidentially destroyed. We will keep a completely anonymous copy of the electronic file indefinitely, from which you will not be able to be identified at all. At the very end of the study, once we have seen a number of children, you and your child will be given a summary of the results.

Is there any risk from taking part? We do not think that the package will be harmful in any way. We want it to be helpful and it has been designed to be fun. The questionnaires and activities are all either designed for children and their parents or carers, or especially adapted for children, and have been approved by researchers who have many years experience of working with children. However if you or your child are distressed in any way by taking part, the therapists working on the study are qualified to deal with this sensitively and appropriately. If this happens, please talk to the researcher, or to one of the therapists: Nedah Hassanali -Research Worker; Claire Tobin, Clinical Psychologist in training, Jonathan Bradley, Clinical Psychologist in training, or Karen Bracegirdle, Research Therapist, 1st Floor Mapother House, De Crespigny Park, London, SE5 8AZ. Tel no: 0203 228 7777/ 07427425411).

Are there any benefits of taking part? We hope that the children will enjoy taking part in the study and will learn some useful strategies for coping with day to day stresses. Both children and adults also sometimes find completing the questionnaires interesting and helpful.

Do I have to take part?

It is up to you and your child to decide whether or not to take part in this study. If you do decide to take part you are still free to stop at any time and without giving any reasons. This will not affect any other help or support that you or your child will be offered.

What happens when the project stops?

When you have finished taking part in the research, you will carry on as usual seeing the team where you were originally looking for help. If this help is available before the project finishes, you will be able to still carry on with the project if you would like to. We will ask you and your child if you would be willing to be contacted regarding future projects, and if you would, we will keep your name and contact details. You will be able to ask us not to contact you at any time, and this will not affect you in any other way. This project is only running for three years from 2011, and we cannot guarantee that the package will still be available after this.

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are thinking about taking part, please continue to read the additional information in Part 2 before making any decision.

Part 2

What if there is a problem?

What if relevant new information becomes available? Sometimes we get new information during a project. If we find out anything new about any of the questionnaires or the package which means it might be harmful or upsetting for you or your child in any way, we will tell you both at once and you can decide whether or not you want to carry on.

What will happen if I, or my child, no longer want to carry on with the study? If you decide you no longer want to take part, you should let us know at once. A member of the research team will talk to you about which parts you no longer want to be involved in (for example, you might not want to come for the package, but feel OK with the questionnaires). We would like to still keep the information you have already given us if this is possible, but we will check this with you as well. You can tell us that you would like us not to keep any information at all about you, and in this case we will destroy all our copies of the information you have given us. This will not affect any other care you or your child might be offered, or your rights in any other way.

Complaints: If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions. (Nedah Hassanali -Research Worker: Department of Psychology, King's College London, Institute of Psychiatry, Denmark Hill, London, SE5 8AF, Tel no: 0207 848 5794/ 07427475940 or Karen Bracegirdle (Research Therapist): South London and Maudsley NHS Foundation Trust, Southwark Targeted CAMHS, 1st Floor Mapother House, De Crespigny Park, London, SE5 8AZ. Tel no: 0203 228 7777/ 07427425411). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure (PALS, The Maudsley Hospital, Denmark Hill, London SE5 8AZ, 0800 731 2864).

Harm: In the event that something does go wrong and you or your child are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against your local NHS Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Will my taking part in this study be kept confidential? All information which is collected about you during the course of the research will be kept strictly confidential. All your answers to the questionnaires and the activities will be kept on paper and on an electronic database. The recordings will be kept as electronic files. They will be kept securely and anonymously and will be identifiable only by a number, not by your name. Your name will be kept separately, with the number, on the database and on paper, so that we can identify your questionnaires and recordings in the future if we need to (for example, if you decide you no longer want to be part of the study). We will only identify your questionnaires for a reason like this. Paper copies of questionnaires will be kept securely by the researchers in a locked filing cabinet

in a locked office. Your details will be kept for up to 12 years, and then will be confidentially destroyed. We will keep a completely anonymised copy of the database indefinitely, from which you and your child will not be able to be identified at all.

The information you give will usually be available only to the research team. However, the researcher will let your team know that you are taking part in the study, and will share with your clinical team any important information that is relevant to the care you receive. In addition, should you give any information, such as criminal disclosures, or information relating to your own, your child's or others safety, which requires action, including passing on information to others, we are legally obliged to pass this information on to services who are able to deal with these concerns.

The recordings will all be confidential and will be kept without your child's name or details in a locked filing cabinet in a locked office, except when the therapist is carrying them to and from meetings. They will be available only to members of the research team.

What will happen to the results of the research study? We intend to publish the results of the research. You will not be personally identified in any report/publication. We sometimes use quotes from participants when we write about the research. In this case we will tell you what we want to write and where it will be seen and check that you agree.

Who is organising and funding the research? The research is organised by the team, who are members of academic and clinical staff at the Institute of Psychiatry, King's College London and the South London & Maudsley NHS Trust. The research is funded by the Guy's & St. Thomas' Charity.

Who has reviewed the study? The study has been reviewed by the North West London REC2: 11/LO/0023.

How can I take part? If you would like to take part in this project, please complete the attached consent form. If you have any questions or concerns about taking part in this study please contact the researchers below.

Contact Details:

Nedah Hassanali (Research Worker): Department of Psychology, King's College London, Institute of Psychiatry, Denmark Hill, London, SE5 8AF, Tel no: 0207 848 5794/ 07427475940

Karen Bracegirdle (Research Therapist): South London and Maudsley NHS Foundation Trust, Southwark Targeted CAMHS, 1st Floor Mapother House, De Crespigny Park, London, SE5 8AZ. Tel no: 0203 228 7777/ 07427425411

Claire Tobin and Jonathan Bradley, (Clinical Psychologists in training), King's College London, Department of Psychology, Institute of Psychiatry, Addiction Sciences Building 3rd Floor, 4 Windsor Walk, Denmark Hill, London SE5 8AF

Appendix 4: Information sheet for children**Information Sheet for Young People
V2 10th April, 2011****Coping with Unusual Experiences (CUES)**

- ★ What is this about? We are asking if you want to be part of a project to find ways to help children or teenagers who have unusual experiences.
- ★ Who are you? What do you do? We work with children, teenagers and adults who are feeling upset or having problems and talk to them to find out what is upsetting them, then we help them find new ways to handle it.
- ★ What are 'unusual experiences'? Lots of children, teenagers and adults have these, and often they are not upsetting at all, but sometimes they can be. They are things like:
 - ☞ *Hearing or seeing things that other people can't*
 - ☞ *Feeling like something weird is going on that other people don't understand*
 - ☞ *Feeling like someone is watching, or following you*
- ★ Why are you asking me? We are asking all children and teenagers aged 8-14 who come to this centre.
- ★ What if I say yes? First, we will ask you and your parent or carer some questions. This is to try to find out more about what causes unusual experiences and what makes them upsetting.

- ★ What happens next? If you say you have unusual experiences and you are feeling upset, we will ask you if you want to try out some new ways of trying to handle them.
- ★ What if I say yes? You will meet with someone who will talk to you about what is happening and ways to help. You will have up to 10 meetings, at a time and place that is good for you and your family. So we can see if the meetings are helpful, some people will have the meetings straight away, and some people will have them after 3 months.
- ★ Will I have to wait? You might. It is worked out by chance – a bit like tossing a coin. We can't choose who waits and who doesn't.
- ★ Can I say no? Yes, you can. It is up to you whether you join in. If you don't want to that is fine – no-one will mind and it won't change anything at school, at home or at the centre. Even if you say yes, you can still change your mind whenever you want and you don't need to tell us why.
- ★ Who will know about this? The things you tell us are private, but we will tell other people who are there to help if we are worried about whether you or someone else is safe.
- ★ Can I find out more? Yes. Ask your parents or carer. We have given them a longer sheet like this one that you can read if you want. If they agree, we can tell you more about joining in on the phone, or we can meet you to tell you more. You can meet us on your own or with your family – it is up to you and your parent or carer.



Thanks for reading the sheet



Appendix 5: Consent form for parents

Title of project: Coping with Unusual Experiences (CUES)
**Names of researchers: Karen Bracegirdle, Nedah Hassanali, Claire Tobin,
Jonathan Bradley**

Please initial boxes:

1. I have read the information sheet dated 10/4/11 for the above project, and one of the researchers has talked to me about it. I have had enough time to think about it and ask questions.

☐

2. I understand that taking part is voluntary and that my child and I are free to withdraw at any time, without giving any reason, and without our medical care or legal rights being affected.

☐

3. I am willing for the researcher to let the team know that my child and I are taking part in the study.

☐

4. I am willing for the researcher to contact my team with any information relevant to my child's care, should this become apparent while we are taking part in the study.

☐

5. I am willing for the researchers to record this information in the team's electronic notes for my child.

☐

6. I give permission for sections of my child's medical notes to be looked at by the researchers, if it is relevant to taking part in this research (for example, to get an address, age or confirm clinical information).

☐

7. I am willing for my and my child's meetings with the therapist and researcher to be audiorecorded.

☐

8. I understand that information relating to me and my child taking part in this study will be stored in an electronic file for up to 12 years.

☐

9. I agree to take part in the above study, and for my child to take part.

☐

Name of parent/carer

Date

Signature

10. I have explained the study to this participant and answered their questions honestly and fully.

☐

Name of researcher

Date

Signature

When completed, 1 copy for the family, 1 for researcher; 1 (original) to be kept in medical notes

Appendix 6: Assent form for young people

ASSENT FORM for Young People – V2 10th April 2011
Coping with Unusual Experiences (CUES)

Names of researchers:

ID:

Thank you for thinking about taking part in this project. The project must be explained to you before you agree to take part. If you have any questions please ask before you decide whether to join in. You will be given a copy of this form to keep.

Please tick the boxes, if you agree and the answer is 'yes':

1. I have read the Information Sheet for Young People and someone has explained it to me and answered my questions. ☐

2. I know that I can change my mind about joining in anytime and I don't have to say why. ☐

3. I know what I say is private unless it is about somebody being hurt. ☐

4. It is OK to record the meetings with me. ☐

5. I want to join in with the project. ☐

If any answers are 'no' or you don't want to join in, don't write your name. If you **do** want to join in, write your name on the line.

Young person's name:

Date:

6. I have explained the study and answered any questions. ☐

Name of researcher

Date

Signature

Appendix 7: RCT Protocol

Screening assessments for children and their caregivers were conducted by a research worker, research therapist or clinical psychologist in training. After screening, those children who reported at least one unusual experience and emotional upset on the Strengths & Difficulties Questionnaire (SDQ; Goodman, 1997) were offered participation in the treatment trial, once all assessment measures had been completed. These young people were randomized to receive the intervention straight away or after a 3-month wait. This was determined by an independent body and could not be influenced by the clinical or research team, irrespective of clinical need. The intervention comprised 9-12 weekly sessions of about 45 minutes with a research CBT therapist. Those randomised to the waitlist condition were assessed again at pre-treatment stage, including any parent measures that had not been completed at baseline. All those who completed therapy underwent post-therapy assessment.

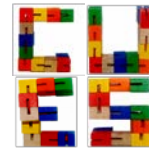
Admin Purposes Only

Participant ID: DOB:

Ax Stage: Gender:

Date of Questionnaire Completion:

Researcher Initials:

**Appendix 8: Parent Questionnaires****Caregiver Questionnaire**

This form should be filled in by the child's main caregiver (usually, this is the child's mother or father). It would help us if you answer all the questions as best you can, even if you are not absolutely certain of your answers or the questions don't seem to apply to your child.

Who is completing this form (e.g., child's Mother, Father, Grandmother, etc.)? :

Is your child: Male Female

When (date) and Where were these people born?:

Your child: DD / MM / YYYY. City: _____;
Country _____

Child's mother: DD / MM / YYYY. City: _ _____ ; Country

Child's father: DD / MM / YYYY. City: _____ ; Country

Did your child ever live away from London? No Yes

Is English your child's first language? No Yes

Which ethnic background best describes your child? (please choose one of the following):

White: British Irish

Other White Background (specify): _____

Black or Black British: Caribbean African

Other Black Background (specify): _____

Asian or Asian British: Indian Pakistani Bangladeshi

Other Asian Background (specify): _____

Oriental or Oriental British: Chinese Japanese

Other Oriental Background (specify): _____

Mixed: White-Black Caribbean White-Black African White-Asian

Other Mixed Background (specify): _____

Other group not included above

(specify): _____

Has your child, or any of your child's relatives, ever seen a doctor about a mental health condition? Please tell us who (e.g., child, or child's brother or sister, mum or dad, grandparent, cousin, etc.) and which condition (e.g., stress or anxiety or nerves, depression, psychosis or schizophrenia, inattention or hyperactivity, autism, eating disorder, etc.):

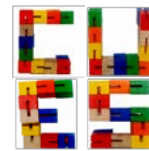
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Participant ID: DOB:

Ax Stage: Gender:

Date of Questionnaire Completion:

Researcher Initials:



When a child is having problems it can cause their parents and carers stress. These questions help us to understand how you are feeling. Please choose the answer that best describes how you have been feeling in the last week. You do not have to think too much, the first answer that comes to mind is usually the best

I feel tense or 'wound up':

Most of the time
A lot of the time
Time to time, occasionally
Not at all

3
2
1
0

I still enjoy the things I used to enjoy:

Definitely as much
Not quite so much
Only a little
Not at all

0
1
2
3

I get a sort of frightened feeling like something awful is about to happen:

Very definitely and quite badly
Yes, but not too badly

3
2

A little, but it doesn't worry me

1

Not at all

0

I can laugh and see the funny side of things:

As much as I always could
Not quite so much now
Definitely not so much now
Not at all

0
1
2
3

Worrying thoughts go through my mind:

A great deal of the time
A lot of the time
From time to time but not too often
Only occasionally

3
2
1
0

I feel as if I am slowed down:

Nearly all of the time
Very often
Sometimes
Not at all

3
2
1
0

I get a sort of frightened feeling like 'butterflies in the stomach':

Not at all
Occasionally
Quite often
Very often

0
1
2
3

I have lost interest in my appearance:

Definitely
I don't take as much care as I should
I may not take quite as much care
I take just as much care as ever

3
2
1
0

I feel restless as if I have to be on the move:

Very much indeed
Quite a lot
Not very much
Not at all

3
2
1
0

I look forward with enjoyment to things:

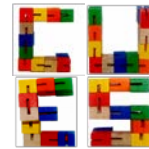
As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

0
1
2
3

Admin Purposes Only

Participant ID: DOB:
Ax Stage: Gender:

Date of Questionnaire Completion:
Researcher Initials:

**I feel cheerful:**

Not at all
Not often
Sometimes
Most of the time

3
2
1
0

I can sit at ease and feel relaxed:

Definitely
Usually
Not often
Not at all

0
1
2
3

I get sudden feelings of panic:

Very often indeed
Quite often
Not very often
Not at all

3
2
1
0

I can enjoy a good book or radio or TV programme:

Often
Sometimes
Not often
Very seldom

0
1
2
3

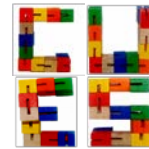
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Participant ID: DOB:

Ax Stage: Gender:

Date of Questionnaire Completion:

Researcher Initials:



These items deal with ways you've been coping with the stress in your life due to your child's problems.

Obviously, different people deal with things in different ways, but I'm interested in how you are trying to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says, how much or how frequently.

1 = I have never done this

2 = I have rarely done this

3 = I have sometimes done this

4 = I have done this a lot

Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true for you as you can.

1. Gone to the cinema or watched TV to think about the problem less.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

2. Criticized yourself.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

3. Drank alcohol or took drugs in order to think about the problem less.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

4. Sought God's help.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

5. Talked to somebody about how you felt.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

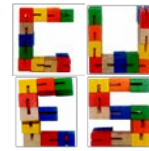
Admin Purposes Only

Participant ID: DOB:

Ax Stage: Gender:

Date of Questionnaire Completion:

Researcher Initials:

**6. Made a plan of action.**

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

7. Put aside other activities to concentrate on the problem.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

8. Looked for something good in what was happening.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

9. Made fun of the problem.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

10. Pretended the problem hadn't really happened.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

11. Given up your attempts to get what you wanted.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

12. Let your feelings out about the problem.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

13. Taken alcohol or drugs to help you get through the problem.

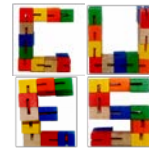
Admin Purposes Only

Participant ID: DOB:

Ax Stage: Gender:

Date of Questionnaire Completion:

Researcher Initials:



1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

14. Turned to work or other activities to take your mind off the problem.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

15. Tried to find comfort in your religion.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

16. Blaming yourself for things that have happened.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

17. Just gave up trying to solve the problem.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

18. Made jokes about the problem.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

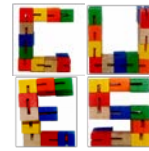
Admin Purposes Only

Participant ID: DOB:

Ax Stage: Gender:

Date of Questionnaire Completion:

Researcher Initials:

**19. Learned to live with the problems.**

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

20. Forced yourself to wait for the right time to do something about the problem.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

21. Taken additional action to try to get rid of the problem.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

22. Kept yourself from getting distracted from other things.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

23. Made sure that you did not make matters worse by acting too soon.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

24. Asked people who have had similar experiences what they did.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

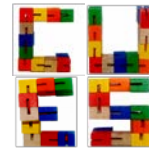
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**25. Tried to see the problem in a different light, to make it seem more positive.**

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

26. Tried to get emotional support from friends or relatives.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

27. Accepted that the problem had happened, and nothing could be done to change it.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

28. Got upset and let your emotions out.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

29. Refused to believe the problem had happened.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

30. Tried to get advice from someone about what to do.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

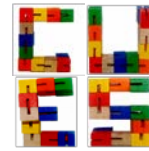
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**31. Tried to come up with a strategy about what to do.**

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

32. Concentrated your efforts on doing something about the problem.

1	2	3	4
Never done this	Rarely done this	Sometimes done this	Done this a lot

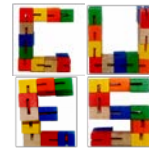
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**IPQ****For the following questions, please circle the number that best corresponds to your views:**

How much do your child's problems affect your child's life?

0 1 2 3 4 5 6 7 8 9 10

*No effect**Severely affects**at all**my child's life*

How much do your child's problems affect your life?

0 1 2 3 4 5 6 7 8 9 10

*No effect**Severely affects**at all**my life*

How long do you think your child's problems will continue?

0 1 2 3 4 5 6 7 8 9 10

*A very**Forever**short time*

How much control do you feel you have over your child's problems?

0 1 2 3 4 5 6 7 8 9 10

*Absolutely**Total**no control**control*

How much control do you feel your child has over their own problems?

0 1 2 3 4 5 6 7 8 9 10

*Absolutely**Total**no control**control*

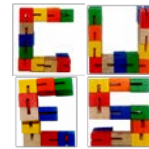
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How much do you think treatment can help your child's problems?

0 1 2 3 4 5 6 7 8 9 10

*Not at all**Extremely**helpful**helpful*

How much do you experience difficulties from your child's problems?

0 1 2 3 4 5 6 7 8 9 10

*No difficulties**Many severe**At all**difficulties*

How concerned are you about your child's problems?

0 1 2 3 4 5 6 7 8 9 10

*Not at all**Extremely**concerned**concerned*

How well do you feel you understand your child's problems?

0 1 2 3 4 5 6 7 8 9 10

*Don't understand**Understand**at all**very clearly*

How much do your child's problems affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

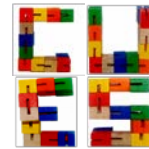
0 1 2 3 4 5 6 7 8 9 10

*Not at all**Extremely**emotionally**emotionally**affected**affected*

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Please list in rank-order the three most important factors that you believe caused your child's problems.

The most important causes for me:-

1. _____
2. _____
3. _____

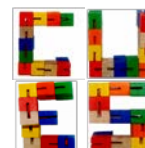
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**WEMBS**

Below are some statements about feelings and thoughts. Please choose the box that best describes your experience of each over the last 2 weeks.

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
1. I've been feeling optimistic about the future	1	2	3	4	5
2. I've been feeling useful	1	2	3	4	5
3. I've been feeling relaxed	1	2	3	4	5
4. I've been feeling interested in other people	1	2	3	4	5
5. I've had energy to spare	1	2	3	4	5
6. I've been dealing with problems well	1	2	3	4	5
7. I've been thinking clearly	1	2	3	4	5
8. I've been feeling good about myself	1	2	3	4	5
9. I've been feeling close to other people	1	2	3	4	5
10. I've been feeling confident	1	2	3	4	5
11. I've been able to make up my own mind about things	1	2	3	4	5
12. I've been feeling loved	1	2	3	4	5
13. I've been interested in new things	1	2	3	4	5
14. I've been feeling cheerful	1	2	3	4	5

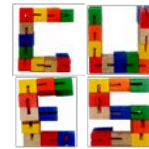
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**SSQ-6**

The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, please list all the people you know, excluding yourself, whom you can count on for help and support in the manner described. Give the person's initials and their relationship to you. For example:

Who do you know whom you can trust with information that could get you in trouble?

No one	1. T.N. (brother)	4. T.N. (father)	7.
	2. L.M. (friend)	5. L.M. (boss)	8.
	3. R.S. (friend)	6.	9.

How satisfied are you with this support?

6 ✓	5	4	3	2	1
Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied

For the second part of the question, please answer how satisfied you are with the overall support you have.

If you have no support for a question, please answer "No one" in the first box, but still rate your level of satisfaction. Do not list more than nine people per question.

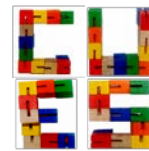
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**Whom can you really count on to be dependable when you need help?**

No one	1.	4.	7.
	2.	5.	8.
	3.	6.	9.

How satisfied are you with this support?

6	5	4	3	2	1
Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied

Whom can you really count on to help you to feel more relaxed when you are under pressure or tense?

No one	1.	4.	7.
	2.	5.	8.
	3.	6.	9.

How satisfied are you with this support?

6	5	4	3	2	1
Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied

Who accepts you totally, including both your worst and your best points?

No one	1.	4.	7.
	2.	5.	8.
	3.	6.	9.

How satisfied are you with this support?

6	5	4	3	2	1
Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied

Whom can you really count on to care about you, regardless of what is happening to you?

No one	1.	4.	7.
	2.	5.	8.
	3.	6.	9.

How satisfied are you with this support?

6	5	4	3	2	1
Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied

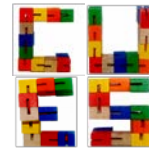
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Whom can you really count on to help you to feel better when you are feeling generally down-in-the-dumps?

No one	1.	4.	7.
	2.	5.	8.
	3.	6.	9.

How satisfied are you with this support?

6	5	4	3	2	1
Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied

Whom can you really count on to console you when you are very upset?

No one	1.	4.	7.
	2.	5.	8.
	3.	6.	9.

How satisfied are you with this support?

6	5	4	3	2	1
Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied

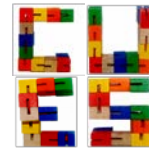
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For each item, please mark the box for Not True, Somewhat True, or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on your child's behaviour over the last six months.

1. Considerate of other people's feelings.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

2. Restless, overactive, cannot stay still for long.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

3. Often complains of headaches, stomach-aches or sickness.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

4. Shares readily with other children (treats, toys, pencils etc.)

- ☐ Not true
☐ Somewhat true
☐ Certainly true

5. Often has temper tantrums or hot tempers.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

6. Rather solitary, tends to play alone.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

7. Generally obedient, usually does what adults request.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

8. Many worries, often seems worried.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

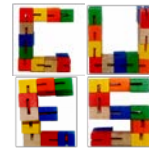
9. Helpful if someone is hurt, upset or feeling ill.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

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10. Constantly fidgeting or squirming.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

11. Has at least one good friend.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

12. Often fights with other children or bullies them.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

13. Often unhappy, down-hearted or tearful.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

14. Generally liked by other children.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

15. Easily distracted, concentration wanders.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

16. Nervous or clingy in new situations, easily loses confidence.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

17. Kind to younger children.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

18. Often lies or cheats.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

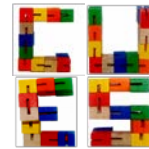
19. Picked on or bullied by other children.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

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20. Often volunteers to help others (parents, teachers, other children).

- ☐ Not true
☐ Somewhat true
☐ Certainly true

21. Thinks things out before acting.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

22. Steals from home, school or elsewhere.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

23. Gets on better with adults than with other children.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

24. Many fears, easily scared.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

25. Sees tasks through to the end, good attention span.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

26. Do you have any other comments or concerns?

27. Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

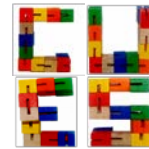
- ☐ No
☐ Yes- minor difficulties
☐ Yes- definite difficulties
☐ Yes- severe difficulties

If you have answered "Yes", please answer the following questions about these difficulties:

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**28. How long have these difficulties been present?**

- ☐ Less than a month
- ☐ 1-5 months
- ☐ 6-12 months
- ☐ Over a year

29. Do the difficulties upset or distress your child?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

Do the difficulties interfere with your child's everyday life in the following areas?

30. Home life

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

31. Friendships

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

32. Classroom Learning

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

33. Leisure activities

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

34. Do the difficulties put a burden on you or the family as a whole?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

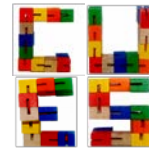
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The next items ask about thoughts or beliefs that your child could have had over the last 2 weeks. For each item, please mark the box for Not True, Somewhat True or Certainly True. Remember to answer all the items as best as you can even if you are not absolutely certain or the item seems daft.

1a. Some people believe that their thoughts can be read. Has your child ever thought that other people could read his/her thoughts?

If 'Not True' please go to question 2a.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

1b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
☐ Only once
☐ 2-4 times
☐ 5 or more times

1c. How much has it affected them?

- ☐ Not at all
☐ Only a little
☐ Quite a lot
☐ A great deal

1d. How much has it made things hard for them at home or school?

- ☐ Not at all
☐ Only a little
☐ Quite a lot
☐ A great deal

2a. Has your child ever believed that he/she was being sent special messages through the television or the radio, or that a programme had been arranged for just him/her alone?

If 'Not True' please go to question 3a.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

2b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
☐ Only once
☐ 2-4 times
☐ 5 or more times

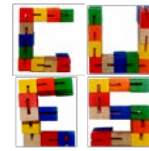
2c. How much has it affected them?

- ☐ Not at all
☐ Only a little
☐ Quite a lot
☐ A great deal

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**2d. How much has it made things hard for them at home or school?**

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

3a. Has your child ever thought that he/she was being followed or spied upon?

If 'Not True' please go to question 4a.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

3b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
- ☐ Only once
- ☐ 2-4 times
- ☐ 5 or more times

3c. How much has it affected them?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

3d. How much has it made things hard for them at home or school?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

4a. Has your child ever heard voices that other people couldn't hear?

If 'Not True' please go to question 5a.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

4b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
- ☐ Only once
- ☐ 2-4 times
- ☐ 5 or more times

4c. How much has it affected them?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

4d. How much has it made things hard for them at home or school?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

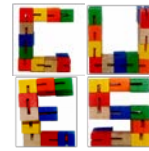
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**5a. Has your child ever thought that he/she was under the control of some special power?**

If 'Not True' please go to question 6a.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

5b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
- ☐ Only once
- ☐ 2-4 times
- ☐ 5 or more times

5c. How much has it affected them?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

5d. How much has it made things hard for them at home or school?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

6a. Has your child ever claimed to know what another person was thinking even though that person wasn't speaking?

If 'Not True' please go to question 7a.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

6b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
- ☐ Only once
- ☐ 2-4 times
- ☐ 5 or more times

6c. How much has it affected them?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

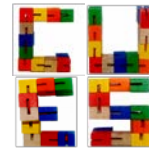
6d. How much has it made things hard for them at home or school?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

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**7a. Has your child ever thought his/her body had been changed in some way that he/she couldn't understand?**

If 'Not True' please go to question 8a.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

7b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
- ☐ Only once
- ☐ 2-4 times
- ☐ 5 or more times

7c. How much has it affected them?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

7d. How much has it made things hard for them at home or school?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

8a. Has your child ever claimed to have special powers other people don't have?

If 'Not True' please go to question 9a.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

8b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
- ☐ Only once
- ☐ 2-4 times
- ☐ 5 or more times

8c. How much has it affected them?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

8d. How much has it made things hard for them at home or school?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

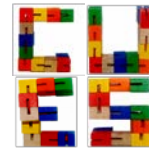
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**9a. Has your child ever seen something or someone that other people could not see?**

If 'Not True' please go to question 10a.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

9b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
- ☐ Only once
- ☐ 2-4 times
- ☐ 5 or more times

9c. How much has it affected them?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

9d. How much has it made things hard for them at home or school?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

10a. If your child has not had any of these experiences in the last two weeks, have they had any of them in the last year?

Please read the list below as a reminder of the experiences we are asking about.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

10b. If your child has had one of these experiences in the last year, please could you check, what type of experience it was?

- ☐ Thoughts being read.
- ☐ Sent special messages through the television
- ☐ Spied on or followed.
- ☐ Heard voices that others could not hear.
- ☐ Under the control of some special power.
- ☐ Known what another person was thinking, even though they weren't speaking.
- ☐ Your body has changed in a way that you could not understand.
- ☐ Having special powers that others don't have.
- ☐ Seen something or someone that others could not see.

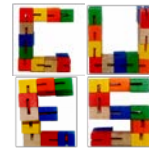
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Participant ID: DOB:

Ax Stage: Gender:

Date of Questionnaire Completion:

Researcher Initials:

**Appendix 9: Child Questionnaires**

For each item please check the box for Not True, Somewhat True or Certainly true. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of how things have been for you over the last six months.

1. I try to be nice to other people. I care about their feelings.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

2. I am restless; I cannot stay still for long.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

3. I get lots of headaches, stomach-aches, or sickness.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

4. I usually share with others (food, games, pens, etc.)

- ☐ Not true
☐ Somewhat true
☐ Certainly true

5. I get very angry and often lose my temper.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

6. I am usually on my own. I generally play alone or keep to myself.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

7. I usually do as I am told.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

8. I worry a lot.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

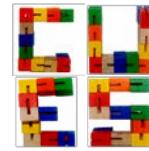


*Well done first
page completed!!*

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Participant ID: DOB:
Ax Stage: Gender:

Date of Questionnaire Completion:
Researcher Initials:



9. I am helpful if someone is hurt, upset, or feeling ill.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

10. I am constantly fidgeting or squirming.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

11. I have one good friend or more.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

12. I fight a lot. I can make other people do what I want.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

13. I am often unhappy, down-hearted, or tearful.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

14. Other people my age generally like me.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

15. I am easily distracted. I find it difficult to concentrate.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

16. I am nervous in new situations. I easily lose confidence.Not true

- ☐ Somewhat true
- ☐ Certainly true

17. I am kind to younger children.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

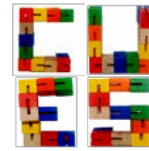


**Well done you have
completed page 3!!**

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Participant ID: DOB:
Ax Stage: Gender:

Date of Questionnaire Completion:
Researcher Initials:



18. I am often accused of lying or cheating.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

19. Often children or young people pick on me or bully me.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

20. I often volunteer to help others (parents, teachers, children).

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

21. I think before I do things.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

22. I take things that are not mine from home, school, or elsewhere.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

23. I get on better with adults than people my own age.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

24. I have many fears. I am easily scared.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

25. I finish the work I am doing. My attention is good.

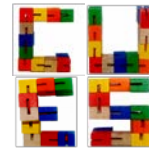
- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

26. Do you have any other comments or concerns?

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Participant ID: DOB:
Ax Stage: Gender:

Date of Questionnaire Completion:
Researcher Initials:



27. Overall, do you think that you have difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

- ☐ No
- ☐ Yes- minor difficulties
- ☐ Yes – definite difficulties
- ☐ Yes – severe difficulties

If you have answered 'Yes' Please answer the following questions about these difficulties.

28. How long have these difficulties been present?

- ☐ Less than a month
- ☐ 1-5 months
- ☐ 6-12 months
- ☐ Over a year

29. Do the difficulties upset or distress you?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

Do the difficulties interfere in your everyday life in the following areas?

30. Home life?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

31. Friendships?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

32. Classroom learning?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

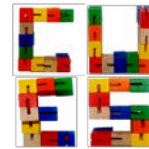
33. Leisure activities?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

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Participant ID: DOB:
Ax Stage: Gender:

Date of Questionnaire Completion:
Researcher Initials:



34. **Do the difficulties make it harder for those around you? (Family, friends, teachers etc.)?**

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal



Well done you have completed the survey!

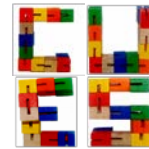
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Participant ID: DOB:

Ax Stage: Gender:

Date of Questionnaire Completion:

Researcher Initials:

**Questions about your thoughts and beliefs.**

These questions ask about your thoughts or beliefs that you may have had over the last 2 weeks. For each question, please mark the box for Not True, Somewhat True or Certainly True.

1a. Some people believe that their thoughts can be read. Have other people ever read your thoughts?

If 'Not True' please go to question 2a.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

1b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
☐ Only once
☐ 2-4 times
☐ 5 or more times

1c. How much has it upset you?

- ☐ Not at all
☐ Only a little
☐ Quite a lot
☐ A great deal

1d. How much has it made things hard at home or school?

- ☐ Not at all
☐ Only a little
☐ Quite a lot
☐ A great deal

2a. Have you ever believed that you were being sent special messages through the television?

If 'Not True' please go to question 3a.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

2b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
☐ Only once
☐ 2-4 times
☐ 5 or more time

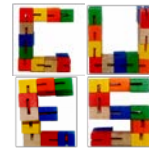
2c. How much has it upset you?

- ☐ Not at all
☐ Only a little
☐ Quite a lot
☐ A great deal

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Participant ID: DOB:
Ax Stage: Gender:

Date of Questionnaire Completion:
Researcher Initials:



2d. How much has it made things hard at home or school?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

3a. Have you ever thought that you were being followed or spied upon?

If 'Not True' please go to question 4a.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

3b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
- ☐ Only once
- ☐ 2-4 times
- ☐ 5 or more times

3c. How much has it upset you?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

3d. How much has it made things hard at home or school?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

4a. Have you ever heard voices that other people could not hear?

If 'Not True' please go to question 5a.

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

4b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
- ☐ Only once
- ☐ 2-4 times
- ☐ 5 or more times

4c. How much has it upset you?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

4d. How much has it made things hard at home or school?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

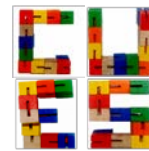
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Ax Stage: Gender:

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Researcher Initials:

**5a. Have you ever felt that you were under the control of some special power?**

If 'Not True' please go to question 6a.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

5b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
☐ Only once
☐ 2-4 times
☐ 5 or more times

5c. How much has it upset you?

- ☐ Not at all
☐ Only a little
☐ Quite a lot
☐ A great deal

5d. How much has it made things hard at home or school?

- ☐ Not at all
☐ Only a little
☐ Quite a lot
☐ A great deal

6a. Have you ever known what another person was thinking even though that person wasn't speaking?

If 'Not True' please go to question 7a.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

6b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
☐ Only once
☐ 2-4 times
☐ 5 or more times

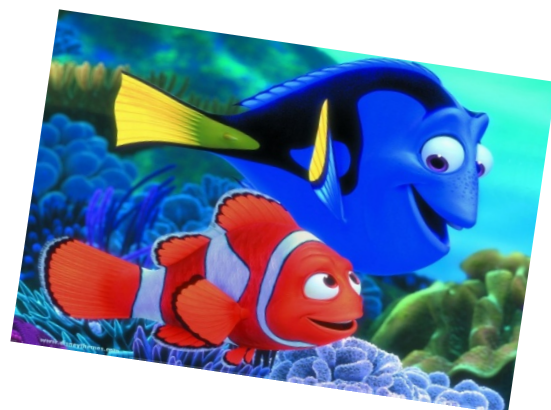
6c. How much has it upset you?

- ☐ Not at all
☐ Only a little

- ☐ Quite a lot
☐ A great deal

6d. How much has it made things hard at home or school?

- ☐ Not at all
☐ Only a little
☐ Quite a lot
☐ A great deal



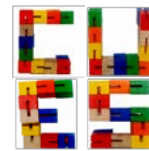
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Ax Stage: Gender:

Date of Questionnaire Completion:

Researcher Initials:

**7a. Have you ever felt as though your body had been changed in some way that you could not understand?**

If 'Not True' please go to question 8a.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

7b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
☐ Only once
☐ 2-4 times
☐ 5 or more times

7c. How much has it upset you?

- ☐ Not at all
☐ Only a little
☐ Quite a lot
☐ A great deal

7d. How much has it made things hard at home or school?

- ☐ Not at all
☐ Only a little
☐ Quite a lot
☐ A great deal

**8a. Do you have any special powers that other people don't have?**

If 'Not True' please go to question 9a.

- ☐ Not true
☐ Somewhat true
☐ Certainly true

8b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
☐ Only once
☐ 2-4 times
☐ 5 or more times

8c. How much has it upset you?

- ☐ Not at all
☐ Only a little
☐ Quite a lot
☐ A great deal

8d. How much has it made things hard at home or school?

- ☐ Not at all
☐ Only a little
☐ Quite a lot
☐ A great deal

9a. Have you ever seen something or someone that other people could not see?

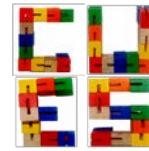
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Participant ID: DOB:

Ax Stage: Gender:

Date of Questionnaire Completion:

Researcher Initials:



If 'Not True' please go to question 10a

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

9b. If true, how often has it happened over the last 2 weeks?

- ☐ Not at all
- ☐ Only once
- ☐ 2-4 times
- ☐ 5 or more times

9c. How much has it upset you?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

9d. How much has it made things hard at home or school?

- ☐ Not at all
- ☐ Only a little
- ☐ Quite a lot
- ☐ A great deal

10a. If you have not had any of these experiences in the last two weeks, have you had any of them in the last year?

Please read the list below as a reminder of the experiences we are asking about

- ☐ Not true
- ☐ Somewhat true
- ☐ Certainly true

10b. If you have had one of these experiences in the last year, please could you check what type of experience it was?

- ☐ Thoughts being read.
- ☐ Sent special messages through the television.
- ☐ Spied on or followed.
- ☐ Heard voices that others could not hear.
- ☐ Under the control of some special power.
- ☐ Known what another person was thinking, even though they weren't speaking.
- ☐ Your body has changed in a way that you could not understand.
- ☐ Having special powers that others don't have.
- ☐ Seen something or someone that others could not see.

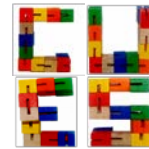
11. From the different thoughts and beliefs we have talked about, which would you consider to be the main one?

- ☐ Thoughts being read.
- ☐ Sent special messages through the television.
- ☐ Spied on or followed.
- ☐ Heard voices that others could not hear.
- ☐ Under the control of some special power.
- ☐ Known what another person was thinking, even though they weren't speaking.
- ☐ Your body has changed in a way that you could not understand.
- ☐ Having special powers that others don't have.
- ☐ Seen something or someone that others could not see.

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Participant ID: DOB:
Ax Stage: Gender:

Date of Questionnaire Completion:
Researcher Initials:



Thinking about this thought or belief...

11a. Is this caused by something inside you or outside you?

- ☐ Completely because of something outside
- ☐ Mostly outside but some of it comes from inside
- ☐ Mix of outside and inside
- ☐ Mostly inside but some of it comes from outside
- ☐ Completely because of something inside

11b. Is this caused by things other people are doing or by events people can't control?

- ☐ Completely what others are doing
- ☐ Mostly what others do but some of it caused by other events
- ☐ Mix of both
- ☐ Mostly other events but some of it is caused by what others do
- ☐ Completely other events

11c. Do you think this is dangerous to you or other people?

- ☐ Yes, definitely
- ☐ A bit
- ☐ Don't know
- ☐ Mostly harmless
- ☐ No, completely harmless



**You've finished the questionnaire, thank you for
answering the questions.**

Appendix 10: Recruitment and Missing data

A possible 163 children aged 8-14 were placed on the CAMHS waiting list over the duration of recruitment for this study (March 2012-March 2013). Three of the children on the list turned 15 years of age before they could be recruited, excluding them from participating. Twenty-seven cases were closed by CAMHS before they were contacted about the study. Thirty-eight parents or their children declined to participate. Forty families were unable to be contact due to a lack of details. One child was recruited to another trial. Ten families withdrew from the study. Data was successfully gathered from 44 parent-child dyads.

Participants were selected for the presence of emotional and behavioural difficulties, and therefore occasionally struggled to complete the full dataset, due to attention, concentration or behavioural problems. The presence of a parent or caregiver was required at first meeting, and other family commitments, including care of (often younger) siblings sometimes constrained data collection. Families often needed a home visit, and their living circumstances were sometimes such that facilities were not available to carry out some assessments (e.g. a separate room to complete the speech sample). A small amount of data was lost through occasional technical failures (e.g. loss of mobile internet connection leading to failure of the survey software to save questionnaire results). For these reasons there was a small amount of missing data. Missing data were replaced by the mean for cases where fewer than 30% of the values were missing (Case mean substitution technique; Fox-Wasylyshyn & El-Masri, 2005). Where missing data exceeded 30% then the particular case was excluded from the analysis where the missing data was required.

Child SDQ data was missing in two cases, a further two cases were missing child PLE data. One case was missing both the child SDQ and PLE data. These cases are excluded from specific analysis where the child data was required.

Two parents did not complete the WEMWBS and three parents did not complete the SSQ-6. In all cases this was due to timing constraints. Nine parents did not complete the FMSS. These nine participants were not significantly different on any clinical or demographic variables to those who completed the FMSS.

Appendix 11: Relationship between Clinical-Demographic and Outcome Measures

Continuous clinical-demographic variables (parent age, child age) were not associated with any of the outcome measures (child PLE severity, parent anxiety, parent depression; Table 15).

Higher levels of parent depression were associated with higher levels of parent anxiety (r_s [44] = .67, $p < .001$).

Table 15: Means, Standard Deviations and Spearman's Correlations between Continuous Clinical-Demographic Variables and Mental Health Status Measures.

	<i>M(SD)</i>	2	3	4	5
1. Child Age (yrs)	11.61 (1.99)	.30	.02	.11	.17
2. Parent age (yrs)	40.34 (9.53)		-.01	-.11	-.08
3. PLE Severity	13.59 (13.38)			.02	.05
4. Parent Anxiety	10.06 (4.90)				.67**
5. Parent Depression	7.52 (4.78)				-

PLE= Psychotic Like Experiences; ** $p < .001$

T-tests showed no significant difference between white and non-white ethnic groups, nor between those with and without a history of family mental health problems on child PLE severity or parent anxiety and depression (Table 16). Independent T-tests showed no significant difference between dyads rated as high or low EE and parent age (t [1,31]=-.36, $p=.719$, ns ; Low EE=40.90, $SD=5.28$; High EE $M=42.41$, $SD=10.55$), or child age (t [1,33]=-.11, $p=.916$, ns ; Low EE=11.59, $SD=2.33$; High EE $M=11.68$, $SD=2.08$). A chi-square test found that ethnicity (white versus non-white) was not reliably related to EE categorisation ($\chi^2(1, 35) = .26$, $p = .610$). A history of family mental health problems was also not reliably related to EE categorization ($\chi^2[1, 31] = 1.37$, $p = .241$, ns).

Table 16: Group differences based on ethnicity and previous family mental health service contact, for continuous parent and child outcome measures.

Outcome Variable	Ethnicity		<i>t</i>	<i>df</i>	<i>p</i>	Previous Family Mental Health Contact		<i>t</i>	<i>df</i>	<i>p</i>
	White	Non-white				Previous Contact	No Contact			
	M (SD)	M (SD)				M (SD)	M (SD)			
Parent Anxiety	10.61 (5.22)	9.47 (4.57)	0.76	42	.450	10.33 (5.11)	9.00 (4.90)	0.72	38	.475
Parent Depression	7.96 (5.36)	7.05 (4.14)	0.63	42	.535	7.80 (4.88)	6.80 (4.98)	0.56	38	.580
Child PLE Severity	12.00 (15.61)	15.61 (12.68)	-0.86	39	.398	13.11 (12.23)	13.00 (14.50)	0.02	35	.983

PLE= Psychotic Like Experiences

Appendix 12: PLE Descriptive Statistics

Table 17: Means, Standard Deviations and Response Prevalence for PLE Endorsement and Descriptive statistics for Associated Impact and Distress.

PLE Item n=40	Descriptive Statistics	Response Prevalence (%)			Associated Distress	Associated Impact
		NT	ST	CT		
	Mean (SD)				Mean (SD)	Mean (SD)
6. Have you ever known what another person was thinking even though that person wasn't speaking? (read minds)	.75 (.84)	50.0	25.0	25.0	.60 (.75)	.50 (.51)
4. Have you ever heard voices that other people could not hear? (heard voices)	.68 (.86)	57.5	17.5	25.0	1.44 (1.09)	1.13 (1.03)
9. Have you ever seen something or someone that other people could not see? (seen things)	.67 (.83)	55.0	22.5	22.5	1.17 (1.15)	.94 (1.06)
3. Have you ever thought that you were being followed or spied upon? (spied upon)	.60 (.78)	57.5	25.0	17.5	1.11 (.94)	1.00 (.94)
1. Some people believe that their thoughts can be read. Have other people ever read your thoughts? (thoughts read)	.48 (.68)	62.5	27.5	10.0	.47 (.74)	.93 (1.00)
8. Do you have any special powers that other people don't have? (special powers)	.46 (.76)	69.2	15.4	15.4	.31 (.48)	.38 (.65)
5. Have you ever felt that you were under the control of some special power? (controlled)	.43 (.71)	70.0	17.5	12.5	1.15 (1.21)	1.15 (1.21)
2. Have you ever believed that you were being sent special messages through the television? (special messages)	.35 (.66)	75.0	15.0	10.0	.60 (.52)	.45 (.52)
7. Have you ever felt as though your body had been changed in some way that you could not understand? (body changed)	.30 (.61)	77.5	15.0	7.5	.73 (.47)	.64 (.92)

PLE= Psychotic Like Experiences; NT, not true ; ST, somewhat true ; CT, certainly true.

Items are rank ordered from the most highly endorsed PLE item to the least; item administration order within the questionnaire is indicated by the item number assigned to each item.

Appendix 13: Exploratory Analyses of Cognitive Model of Caregiving

Table 18: Binary Logistic Regression Analyses Predicting the Odds of Scoring High on Expressed Emotion based on Parent-reported Child Difficulties.

Predictor	95% CI for Odds Ratio			
	B (SE)	Lower	e ^β (odds ratio)	Upper
Constant	-.91 (1.33)			
Parent-reported Child Difficulties	-0.14 (0.82)	.98	1.14	1.35

Note: Pseudo $R^2 = 0.15$ (Nagelkerke). Model $\chi^2(1) = 3.46$, $p = .063$, *ns*.

Table 19: Binary Logistic Regression Analyses Predicting the Odds of Scoring High on Expressed Emotion based on Levels of Avoidant Coping.

Predictor	95% CI for Odds Ratio			
	B (SE)	Lower	e ^β (odds ratio)	Upper
Constant	-0.64 (1.75)			
Avoidant Coping	0.14 (0.12)	0.91	1.15	1.47

Note: Pseudo $R^2 = 0.07$ (Nagelkerke). Model $\chi^2(1) = 1.48$, $p = .224$, *ns*.

Table 20: Binary Logistic Regression Analyses Predicting the Odds of Scoring High on Expressed Emotion based on Levels of Social Support Availability.

Predictor	95% CI for Odds Ratio			
	B (SE)	Lower	e ^β (odds ratio)	Upper
Constant	2.73 (1.00)			
Social Support	-0.50 (0.31)	.33	.61	1.11

Note: Pseudo $R^2 = 0.12$ (Nagelkerke). Model $\chi^2(1) = 2.83$, $p = .093$, *ns*.

A Multi-perspective Service Audit and Evaluation of the Child Care Assessment Team (CCAT)

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Abstract

The '*Bearing Good Witness*' report (CMO, 2006) recommended that expert witness teams obtain feedback from relevant professionals about the quality of their evidence. Feedback is crucial to ensure both the provision of best quality evidence to relevant professionals, and an acceptable experience for those being assessed. An audit of the expert witness service provided by the Child Care Assessment Team (CCAT) obtained feedback from solicitors, children's guardians and social workers ($n=15$) using a structured interview. Results indicated a high level of satisfaction with the team's responsiveness, the utility and structure reports, the consequent benefits for clients and the professional's ability to obtain funding for future commissioning. A second structured interview was used to obtain feedback directly from parents, children and foster carers previously assessed by CCAT ($n=13$). Being assessed as part of child care proceedings can be a stressful and difficult experience for parents and children, and understandably many did not want to revisit their experience by participating. Consequently, parental and child responses were low; more than three-quarters of respondents were foster carers. Results indicated good satisfaction with the team's facilitation of understanding, the clinic facilities and appointment schedule, the impact of the assessment process and the provision of feedback. The results of this audit and service evaluation were fed back to CCAT, and resulted in changes being implemented as part of ongoing service development.

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Background

CCAT is a National and Specialist Service in the National Health Service (NHS). They provide expert evidence in relation to child care proceedings. Sir Liam Donaldson's report '*Bearing Good Witness*' (CMO, 2006) proposed that medical expert evidence should be provided as a public service by multi-disciplinary teams (MDTs) as a core component of the NHS's work to safeguard children. In addition, The National Society for the Prevention of Cruelty to Children (NSPCC) recommends that "*the provision of expert witness testimony in complex care cases will best serve the interests of the child if presented from the foundations of multidisciplinary assessment*" (NSPCC, 2007, p.4). CCAT is made up of professionals from the disciplines of Psychology, Psychiatry and Social work, and is a good example of such a multidisciplinary assessment approach.

The ACE Report (Tucker *et al.*, 2011) was established to take forward the recommendations of *Bearing Good Witness*; it found that MDT working was highly regarded by clinicians, children's guardians, lawyers, judges and local authorities. It identified the advantages of mutual professional support, the capacity of teams to identify the need for additional assessments and to carry these out assessments, and the ability of teams to make informed and specific recommendations. A report from the Family Justice Review Panel (Norgrove, 2011) suggested that courts should instruct an MDT to take forward all the assessments needed in a child care proceedings case, unless there was a clear reason not to do so. The MDT approach was expected to better support training and peer review by bringing the work of expert witnesses together under the auspices of one body (i.e. the NHS).

There have been a number of recent UK cases involving expert witness evidence (e.g. the Angela Canning, Sally Clark and Trupti Patel cases; '*Who would harm our baby?*', 2013) which have questioned the admissibility of poor expert testimony. As this service evaluation was being conducted, a review of 126 expert witness psychology reports was published by Ireland (2012). It found two-thirds of the reports to be of 'poor' or 'very poor' quality. Results indicated a wide variability across a range of issues including the inappropriate use of psychometrics, poor clarity of writing, a lack of objectivity (i.e. the absence of support for opinions and uninformed psychological statements), and issues of sensitivity (i.e. inappropriate comments and unusual observations; Ireland, 2012). Ireland's work has progressed the development of 'quality criteria', however it remains the case that professionals attached to a case are left to judge the quality of expert witness reports. CCAT is eager to advance standardised monitoring of the quality of expert reports.

CCAT Referral and Assessment Process

CCAT is usually instructed by a solicitor, who supplies a Letter of Instruction (LOI). The solicitor may be acting on behalf of Social Services or the children's court-appointed guardian. When the team receives an LOI it meets to discuss the appropriateness of the case and the time-scale. If the team decides to take the case it will supply the schedule of fees and a summary of team member's qualifications to the solicitor, who will in turn provide all the relevant legal documents that detail the family's history. Once funding has been approved a schedule of appointments will be supplied by CCAT.

CCAT tailors assessments to the individual needs of the case, but will often include cognitive assessment, developmental assessment, risk assessment, mental health assessment, observation of contact between parents and children, and assessment of behavioural and emotional difficulties. Parents are usually interviewed individually, with additional joint interviews for couples. Individual interviews with each child are also conducted. Foster carers, carer relatives and extended family are interviewed, as necessary. Information is obtained from each child's school. Given the scope of such an assessment, clinicians from the team will usually meet with children, their parents, foster carers and other family members on several occasions. Assessments are usually conducted at the clinic in the Maudsley Hospital, London.

The assessment forms the basis of a comprehensive report for the court, which contains recommendations on placement needs, contact arrangements, education and treatment needs. Team members may also attend court hearings to further explain their findings and recommendations. The outcome of the assessment may contribute to a court decision that children be placed with extended family members, be placed outside of the family or stay with immediate family, with advice for future support.

Evaluation and audit of the service

CCAT's service users are a diverse group, including professionals, families and carers. This study comprised of (i) an audit of the service based on professional service users feedback and (ii) an evaluation of the service based on feedback from parents, children and foster carers. Results from the audit and service evaluation are presented separately.

Professional Perspective

The first part of this study is an audit of the CCAT service based on feedback from relevant professionals (Social Workers, Guardians and Solicitors).

Providing healthcare professionals with data about their performance in the form of audit and feedback can improve current practice (Jamtvedt, Young, Kristoffersen, O'Brien, &

Oxman, 2006). In line with this model, results were presented to the team, which facilitated the instigation of practice improvements to ensuring the ongoing 'supply' and 'quality' of medical expert witnesses, as outlined in *'Bearing Good Witness'* (CMO, 2006). CCAT is a self-funded service and is dependent on repeat work from professional service users. Feedback is therefore important to the teams continued existence, and to ensure satisfaction.

Foster Carer, Parent and Child Perspective

The second part of the study sought to evaluate the service provided to foster carers, parents and children by asking directly about their experiences of the CCAT assessment.

Foster care has been described as a unique hybrid of both 'work' and 'family' (Blythe, Wilkes, & Halcomb, 2013). Foster carers and carer relatives are essential in supporting children at the centre of child care proceedings. In the CCAT assessment foster carers provide informant accounts about a child, and play an essential role in ensuring that children can attend appointments.

The potential of distress for parents and children due to an assessment has been previously acknowledged, and is understandable given the depth of assessment and potential outcomes, (Booth & Booth, 2004; Brophy, Jhutti-Johal, & McDonald, 2005). CCAT remain aware of the importance that their assessments do not unduly compound an already distressing experience for parents and children, balanced with the need to provide a comprehensive assessment. The views of family court litigants are often overlooked when evaluating the court process (Hunt, 2010). Those that do consider the impact on family members have used the views of professionals to assess the benefits for children and parents (e.g. Tucker *et al.*, 2011). Three important themes for parents involved in child care proceedings have been identified: the extent to which parents felt that (i) their views were taken into account, (ii) the process was impartial and (iii) the decisions were adequately understood and the decisions were soundly based (Hunt, 2010). In addition, the importance of the child's view was addressed by the Family Justice Review Panel (Norgrove, 2011), which stated that, "*Young people should, as early as possible in a case, be supported to be able to make their views known*" (p. 321).

Summary

CCAT strives to promote the protection and the best interests of the children, while balancing this with respecting the child's right to family life. This constitutes a significant challenge, especially where individual service users have differing expectations, objectives and opinions. Two structured interview schedules were developed to elicit feedback from the broad spectrum of service users (both professional and family members or carers), and to provide a multi-perspective view of the expert witness service provided.

Method

Design

Feedback from relevant professionals, foster carers, parents and children was elicited using structured interviews to provide data for the service evaluated.

Participants

Seven consecutive cases were assessed by CCAT over 16 months (January 2010 to April 2011). Contact details were available for 61 participants involved in these seven cases: Seven social workers, 19 Solicitors, seven mothers, two fathers, four guardians, one carer relative, 11 foster carers, and 10 children.

Twenty-nine people provided feedback: Three social workers, eight solicitors (including four lead solicitors), two mothers, one father, four guardians, one carer relative, nine foster carers, and one child.

Non-responses

Professionals

Eleven solicitors did not provide feedback. Solicitors were often out of the office on court duty, or were too busy to take a call when they were contacted. Following several telephone attempts, five solicitors remained unreachable. Another five solicitors no longer worked for the same firm. One solicitor could not give feedback because she did not feel she could sufficiently remember the case, or the evidence supplied by CCAT. One social worker was also unreachable by telephone. Three social workers no longer worked in the same team.

Foster Carers, parents and children

In the cases where the child was no longer in the care of the foster carer that had accompanied them to the assessment, the foster carer was still interviewed for their experience of the assessment process. There was no reply from one foster carer, and another foster carer declined our invitation to provide feedback due to time constraints. None of the children from any of the seven national CCAT cases had been returned to the care of their parents. In many cases the children had changed foster placement, social worker, or both, making contact difficult. Only children above the age of twelve were considered for inclusion, five children were too young to be included. One child declined to participate via her foster carer. There were no contact details available for three children who had moved placement since their assessment. Three mothers declined to give feedback when contacted. One stated that the experience was still too distressing to revisit. A further two mothers were unreachable despite a number of attempts to contact them. There were no contact details available for one father. As outlined in similar research (Freeman & Hunt,

1998) the critical aspects of what else may have been going on in parents' lives at the time of the court proceedings may have contributed to the inability to track down parents.

Procedure

Ethical approval was obtained from the South London and Maudsley NHS Trust CAMHS Audit Committee. The lead solicitors, children's guardians and social workers, parents and foster carers from the identified cases were initially contacted by letter (Appendix 1) and invited to take part in the study. Further contact was then made by telephone to either conduct telephone interviews at the time of the call, or to arrange an appointment time that was convenient. Two social workers and one guardian preferred to respond by email or post. For all remaining cases, feedback was obtained via a telephone interview lasting approximately 15 minutes.

After the initial ten interviews were conducted (solicitors= 3; children's guardian= 2, social workers= 3, foster carers= 2) the clinical team reviewed the interview items. In the intervening period since data collection had begun, a restructuring of the legal aid system was released following a government consultation and the subsequent Bill (Ministry of Justice, 2010; Ministry of Justice, 2011a). The Legal Aid Reform Consultation (Ministry of Justice, 2011b) resulted in a 10% reduction in expert witness rates. These developments were expected to impact on professional views of CCAT funding, and additional questions related to cost-effectiveness and commissioning were included for professionals. Amendments were also made to remove a number of questions from the family interview that were not relevant (for example asking if they had been offered tea or coffee, as facilities do not exist to accommodate this).

Measures

Two structured interviews were developed by the clinical team: one for relevant professionals (Appendix 2) and one for use with parents, children and foster carers (Appendix 3). They contained both quantitative and qualitative items.

Quantitative items: The majority of items were answered using a 5-point Likert scale to determine the extent of agreement (strongly agree to strongly disagree) or satisfaction (very satisfied to very dissatisfied) in specific areas. The remaining items were answered using a binary yes-no response (e.g. *'Did we provide enough toys?'*).

After completing the quantitative items for each domain the participant was also asked to comment on *'what CCAT could do differently'*. This question was designed to elicit qualitative responses.

Analyses

Quantitative data are summarized using descriptive statistics. Excel (Microsoft Office) was to calculate percentages at each point in the Likert scale for each question. Qualitative responses were categorised according to the issues being examined in the structured interview. Statistical analyses were carried out using SPSS for Windows (Version 20.0), to firstly examine any group differences between solicitors and other professionals, and secondly to examine any differences between foster carers and family members.

Professional Perspective

Aims

The first aim of the project was to obtain qualitative and quantitative feedback from relevant professionals (social workers, guardians and solicitors), related to the following domains:

1. Utility of Report
2. Responsiveness of the team
3. Structure
4. Objectiveness
5. Client Benefits
6. Funding

1. *Utility of the Report*

Unrealistic levels of contact and plans for trial rehabilitation made by expert witness teams can cause concern to local authorities under increasing financial strain (Tucker *et al.*, 2011), and in turn, can cause anxiety for social workers who find it difficult to prepare the children for such outcomes. The current study examined the utility of CCAT assessment reports based on how appropriate, realistic and valuable relevant professionals believed the report and related recommendations were.

2. *Responsiveness of the Team*

The Family Justice Review (Norgrove, 2011) outlines that the growth in the use of experts has contributed to unjustifiable delays in proceedings, and recommends that the commissioning of an expert's report must not cause delay on proceedings that could have an impact on a child's welfare. Professionals were asked for feedback on CCAT's efficiency of responding, assessment and filing the report.

3. *Structure*

Using NHS teams has been thought to better ensure supply and high quality of expert witness reports. Civil Procedure Rules (CPR) provide guidelines on how reports should be formatted and presented; however Ireland (2012) found high variability in the structure of reports. The structure of CCAT reports was considered through professional feedback on length and presentation. Ireland (2012) also noted that many reports over-relied or misused psychometrics and had an absence of support for opinion. The current study asked

professionals for feedback regarding the information included, such as verbatim interviews and psychometry.

4. Objectiveness

During the Family Justice Review (Norgrove, 2011) consultation process, the Academy of Experts expressed concern that a team of experts would lack the flexibility and independence of a single expert. Ireland (2012) highlighted issues with reports having an absence of support for opinion and using emotive terms including those that could prejudice a case. Ireland (2012) also raised concerns about the sensitivity of many of the reports reviewed where authors had made unusual, inappropriate and irreverent observation about clients (e.g. *"She was dressed in a low-cut pink dress"*). This project aimed to get feedback from professionals about their opinion of the objectivity of the CCAT assessment.

5. Client benefits

An MDT expert witness assessment has been noted to have several benefits for clients. Tucker *et al.* (2011) posited that a reduction in the number of people and places that the child has to encounter in comparison with assessments by separate experts was an advantage of having an MDT expert witness assessment. This finding is supported by the recommendations of the Munro Review of Child Protection (Munro, 2011), which highlighted that children and parents valued continuity in the professionals that they were dealing with. The report also noted that an MDT approach facilitated working in an age-appropriate way, as a range of professional perspectives contributed to the assessment process. Furthermore, MDT assessments could recommend appropriate therapeutic packages, due to the breadth of knowledge within the team.

Parents have been found to misunderstand the decisions made by the court and the reasons for such a decision, including expert witness evidence (Freeman & Hunt, 1998). The current study asked professionals about their client's understanding of the outcome of the report, and their client's agreement with the outcome, as well as the benefits for individual family members.

6. Funding

Professionals included in the ACE Report (Tucker *et al.*, 2011) saw potential for improved value for money and reduced costs to the legal and care systems through the use of MDT expert witnesses. A full financial appraisal was not completed, as only complex cases were included in the ACE pilot, which would have impacted on an economic review. Therefore comparison regarding the costs of expert witness services was not possible; however professionals were able to offer a view on whether the services provided represented good

value for money. The majority of professionals surveyed by Tucker and colleagues (2011) felt that a report from a MDT would provide better value for money both in the short and long-term. For example, the potential for contested hearings was reduced because there was likely be less scope to challenge a team opinion, resulting in a saving of court time and legal costs. National cases undertaken by CCAT are typically complex, multi-issue cases, similar to those included in the ACE pilot. To assess funding, professionals were asked for feedback on securing funding from the Legal Services Commission (LSC), the likelihood that they would instruct CCAT again and the competitiveness of the rates.

Results

Figure one outlines the breakdown of respondents by profession. Over half of the respondents were solicitors. As outlined in figure two, over half of professionals had had the team recommended by a colleague. Quantitative feedback provided by professionals (appendix 4) is described below.

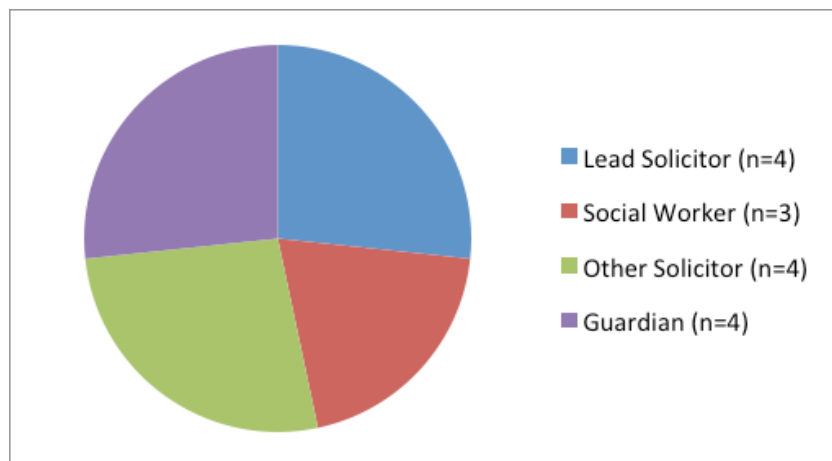


Figure 1: Breakdown of respondents by profession

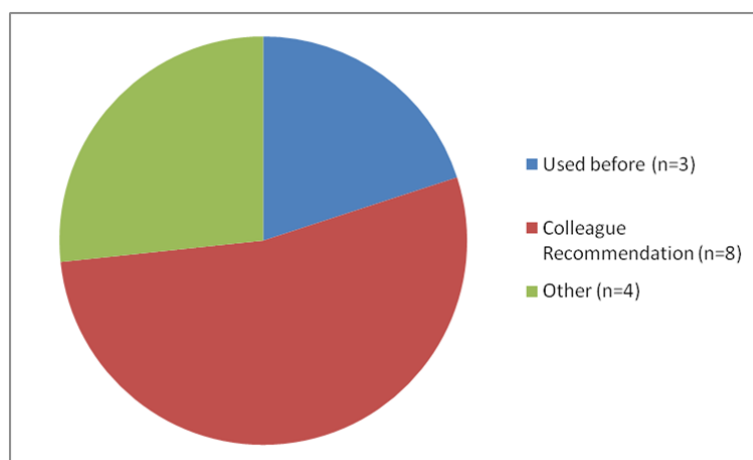


Figure 2: How professional service users first heard about CCAT services

1. Utility of the Report

Results indicated that social workers, guardians and solicitors ($n=15$) had high levels of agreement that the recommendations of the report were clear and concise. Eighty per cent of professionals either agreed or strongly agreed that the report was clear and concise, made a valuable contribution to the court's decision making and made a valuable contribution to the respondent's own report writing (Appendix 4).

'Please comment on what CCAT could do differently.'

Some professionals found the recommendations for the children unfeasible, but others reported the advantage of having the report in accessing supports.

"The raft of recommendations was not possible to replicate in the community. This is not helpful for children." Participant 24C (Guardian).

"The recommendations were far too costly and unrealistic. A residential program was recommended. The Local Authority could never have afforded this. Referral to a Tier four service was also recommended. This was not suitable." Participant 21C (Social Worker).

"The work that the experts did was invaluable and helped access supports for the child more quickly." Participant 54F (Guardian).

2. Responsiveness

Professionals were asked how satisfied they were with the information that they had about the team's services prior to them being appointed by the court: 71% were very satisfied or satisfied with this information. No respondent reported being dissatisfied with the length of time it took to respond to the initial enquiry, communication during the referral stage, or the time taken to carry out the assessment from the date of the referral. The majority (71%) were satisfied with the time taken for the report to be filed following the assessment, however 14% responded with average satisfaction and a further 14% were dissatisfied.

'Please comment on what CCAT could do differently.'

Professional participants provided practical suggestions and areas for improvement in providing information during the assessment process:

"An interim meeting half way through would have been useful to get the hospital's thoughts." Participant 41E (Social Worker).

"Information about the team could have been provided in a more detailed and better format such as a brochure or booklet." Participant 8C (Guardian).

"The team invited the professionals to discuss the report, but this did not clarify anything and just reiterated the report." Participant 18C (Other solicitor).

3. Structure of the Report

More than half the professional sample (53%) found the report too long, however all respondents agreed, or strongly agreed that the presentation of the report was good. In addition, all responders agreed or strongly agreed that CCAT showed evidence for the views it made and was clear on how it had reached its conclusions. The majority agreed or strongly agreed that the inclusion of verbatim interviews had been helpful (80%), however more than one-third (36%) did not agree that the psychometry made sense. In addition 40% did not agree that they understood the implications of the psychometry.

‘Please comment on what CCAT could do differently’

The length of reports was criticised by a number of professionals:

“There was too much duplication in the appendices and in the body of the report leading to duplication.” Participant 62G (Lead solicitor).

“The report repeated itself in a number of places. All the details of the interviews may not be needed for lawyers.” Participant 18C (Other solicitor).

“It was a complex case and the report needed to be as long as it was.” Participant 8C (Guardian).

“It would have been helpful to have a summary. Talking it to the adoption panel meant going through more than 200 pages.” Participant 41E (Social Worker).

4. Objectiveness

The majority of respondents agreed or strongly agreed that the report was objective (93%), sensitively written (72%), and sensitive to issues of culture and diversity (67%). Professional opinion was divided on whether the report reduced disputes and time in court or reduced disputes between parties; half agreed or strongly agreed with these items.

‘Please comment on what CCAT could do differently’

Professionals provided no qualitative feedback concerning the objectiveness of the report.

5. Client Benefits

All respondents believed that their clients had understood the report, but 79% of professionals believed that their clients disagreed or partially disagreed with the outcome of the report

‘Please comment on what CCAT could do differently’

Professionals raised some concerns about the comprehensibility of reports for family members:

"The children don't understand the report but it is useful for planning. The parents don't understand. They have cognitive difficulties." Participant 42E (Guardian).

"The report was too technical for the Mum and Dad as they have cognitive difficulties. Mum and Dad were invited to a feedback meeting." Participant 41E (Social Worker).

6. Funding

Opinion about funding was divided: more than half of respondents (57%) agreed or strongly agreed that it was difficult to secure funding, however 60% agreed that CCAT rates were competitive. Half of respondents would instruct CCAT again based on the quality of the report in relation to the fee charged.

'Please comment on what CCAT could do differently'

Many professional respondents thought the assessment represented good value for money, and they highlighted the quality of the report in supporting this statement. There was an acknowledgement of the current financial climate within the LSC however.

"I do think that it is worth the money." Participant 62G (Lead solicitor).

"It was difficult to secure funding from the LSC because it was expensive and seemed excessive to the LSC." Participant 18C (Other solicitor).

"It was expensive, but then again it is a lot of work." Participant 68G (Other solicitor)

"In comparison to other teams they [the team] charge high fees, but you pay for what you get, the quality was also higher." Participant 54F (Guardian).

Statistical Analyses

There were no significant differences between solicitors and other professionals on their agreement with statements relating to clarity of the team's recommendations, the value of the report to the court's decision making, the information provided by the team, the team's, the teams responsiveness in terms of filing and assessing, the report's objectivity and sensitively (Mann-Whitney (15) $U = 33$, $p = .53$; Mann-Whitney (14) $U = 20$, $p = .58$; Mann-Whitney (14) $U = 17.5$, $p = .35$; Mann-Whitney (14) $U = 24.5$, $p = .95$; Mann-Whitney (14) $U = 10$, $p = .056$; Mann-Whitney (15) $U = 28$, $p = .99$; Mann-Whitney (15) $U = 24$, $p = .62$; Mann-Whitney (15) $U = 16.5$, $p = .16$, respectively).

Foster Carer, Parent and Child Perspectives

Aims

The second aim was to evaluate the service from the perspective of the foster carers, parents and children involved in the proceedings by obtaining qualitative and quantitative feedback in the following domains:

1. Facilitation of the client's understanding
2. Satisfaction with facilities and the appointment schedule
3. Impact of the assessment process
4. Provision of feedback sessions

1. Facilitation of the client's understanding

The expert witness team play an important role in facilitating the client's understanding (Brophy *et al.*, 2005). Levels of stress and anxiety can make it difficult for parents to retain information and ask meaningful questions. Hunt (2010) highlights the importance of access to good information for parents throughout the proceedings process. In particular, parents have reported that they want more information about what to expect (Freeman & Hunt, 1998). Children involved in proceedings have also reported a lack of information about the role of the expert (Ruegger, 2001). This was associated with feelings of exclusion and confusion. This study asked parents, carers and children about their understanding of why the CCAT assessment was being done, the information they had access to, and the opportunity they had to ask questions during the assessment process.

2. Satisfaction with facilities and appointment schedule

Practical implications of needing to travel long distances with young children to attend appointments have been highlighted by Munro (2011). Parent, carer and children's perceptions of clinic facilities and appointment schedules were sought.

3. Impact of the assessment process

Hunt (2010) found that 84% of parents involved in family justice system proceedings had above normal levels of stress. Freeman and Hunt (1998) report that parents may feel humiliated by the process of having their parenting called into question. They also note that parents may fear that this will become known within their wider communities and families, and this may be a particularly salient issue for Black and Minority Ethnic (BME) families (Brophy *et al.*, 2005). Moorhead and colleagues found that although litigants with positive outcomes were more likely to be satisfied with their court experience, outcomes in themselves did not guarantee satisfaction. Rather, their findings suggested that it was the

judgment about the fairness of the process, that was most important in influencing the level of satisfaction for parents (Moorhead, Sefton, & Scanlan, 2008).

Children often feel they have no choice about seeing an expert; in one study over half said that they would not do it again if given the choice (Ruegger, 2001). Children's negative perceptions of the assessment process were due to unfamiliar environments, stigma related to seeing a mental health professional, the brief nature of the relationship with the expert, and the nature of their discussions. The current study asked parents, children and foster carers whether the team had helped them to feel less anxious or worried, and had thought about their strengths.

Parents often feel that an MDT expert witness' opinion was likely to be very influential in the decision-making process, and could be difficult to challenge. This may lead to parents and other family members feeling overpowered, with no scope to seek an alternative view (Tucker *et al.*, 2011). Conversely, an MDT may be perceived as independent by parents, thus assisting parents who found it difficult to work with the local authority to engage with the assessment process. In particular, BME parents have reported that they had not been understood, or did not know if they had been understood, in the decision-making process (Brophy *et al.*, 2005). This is a salient issue for CCAT; almost one-third of families referred to CCAT are from BME groups (Redfern, Cosgrave & Jacobs, 2012). Previous research within the CCAT service also highlighted that 40% of mothers and 43% of fathers referred to the team had a history of mental health disorders (Redfern *et al.*, 2012). Parental mental illness or learning disability has been found to cause parents to feel stigmatized during child care proceedings (Freeman & Hunt, 1998; Booth & Booth, 2005). The current study asked parents, children and carers whether they felt that the team had tried hard to understand them and their family. They were also asked whether they felt listened to, and whether they had found the team respectful and supportive or had found the interviews too challenging.

4. Provision of Feedback Sessions

Reports indicate that foster carers often lack critical information that would help them in their fostering tasks, due to confidentiality constraints in legal proceedings (The Fostering Network, 2008). Feedback sessions can be useful for parents, children and foster carers to understand the assessment experience and the rationale for the conclusions drawn by the team. Parents, children and carers were asked if they had had a feedback session, and whether this had been useful, or would have been useful.

Results

Breakdown of participants

Nine foster carers and one carer relative responded. Only three parents (two mothers, one father) and one child provided feedback. Factors impacting on the recruitment of parents and children included willingness to participate and ability to contact. Quantitative feedback provided by foster carers (Appendix 5) is described below. Due to the small quantity of feedback from parents and children, these results are presented separately (Appendix 6).

1. Facilitation of the foster carers' understanding

The majority of foster carer respondents (80%) were satisfied with the amount of information they received about the assessment following their initial meeting with the team. The same number either agreed or strongly agreed that they understood why the assessment was being done and had been given the opportunity to ask questions to the team. All the foster carer respondents agreed that they understood the questions that were asked during the assessment.

'Please comment on what CCAT could do differently'

Foster Carers described feeling unsure about what would happen as part of their assessment. In particular, they recommended that improved information would help them to manage children's needs and expectations:

"We didn't know what would happen on the day. We didn't know to bring lunch. We thought we would have been able to go out. We thought we would have been able to leave the children." Participant 13B (Foster Carer)

"We had no information beforehand. Just a letter came in the post, we didn't know what it was all about. The foster carers got no information, just appointment letters. It would have been useful to have had contact before the day with the team...We didn't know how long we were going to be there either. We couldn't plan the day. I have other children to think about." Participant 48E (Foster Carer)

"It would have helped to know what they were going to be doing. We didn't expect the child's parents and sisters to be there. It was very confusing for the child. We could have prepared her if we had know that they were going to be there" Participant 48E (Foster Carer)

2. Foster carer satisfaction with facilities and the appointment schedule

Only half of foster carers reported that they had been provided with toys. Interpreters were not needed by any respondent. There was one case of a physical disability, and that was

adequately catered for by the team. Seventy per cent of foster carers were given the appointment schedule on time and 89% had adequate notice of changes.

‘Please comment on what CCAT could do differently’

Suggestion were made that CCAT could better tailor assessment days with practical and childcare needs in mind:

“It was a full-on day and the child was asleep when she was needed. It takes her a long time to wake up and because she is so little the day did not show her at her best. They should have taken into account her sleeping pattern.” Participant 51E (Foster Carer)

“We got the plan, but they were not good times for us. We had 9am appointments, but we live 60 miles away. This was fed back to the team but no adjustments were made.”
Participant 66G (Foster Carer)

3. Impact of the assessment process on foster carers

The majority of foster carers (90%) agreed that the team had tried hard to understand them. The positive impact of the assessment was supported by high levels of agreement that the team had helped foster carers feel less anxious and worried (89%) and listened to what they had to say (90%). All foster carer respondents agreed or strongly agreed that the team were supportive and respectful. The majority of foster carers (71%) agreed that the team had considered their positive qualities, and in 86% of cases the team had considered the positive role they might have in the child’s future.

Foster carers’ opinions were divided on the benefits of the assessment; 44% agreed or strongly agreed with the statement ‘I didn’t feel I gained anything from coming here’. The majority (70%) believed that the process had helped them to think about things that had happened to the children. Half of respondents agreed or strongly agreed that they had learned something from the assessment, however 57% disagreed or strongly disagreed that they would do something different because of the assessment. In addition, 70% of foster carers found the interviews too challenging and difficult.

‘Please comment on what CCAT could do differently’

One foster carer particularly noted the impact of the assessment process on the child:

“The child was drained and upset afterwards... The child cried all the way there and slept all the way back. It was an exhausting process.” Participant 15B (Foster Carer)

“The interviews were too challenging and difficult for the child. They were asked to do things that they wouldn’t normally do in front of strangers.” Participant 49E (Foster Carer)

A number of foster carers provided positive additional feedback about the experience of the assessment process:

"At the time they [the team] were very supportive and available by phone." Participant 15B (Foster Carer)

"The Maudsley were wonderful to help us understand the child and the situation more." Participant 14B (Foster Carer)

Foster carers felt that they could have been more involved in the assessment procedure:

"There was a lot of waiting around. We were not involved... They could have involved the foster carers more. It would have been nice to be able to watch through the two-way mirror, in order to get more information about her behaviour. I never saw that behaviour with me that was described by other people." Participant 14B (Foster Carer).

4. Provision of feedback sessions to foster carers

Only a third of participants reported having had a feedback session with the team about the findings of the assessment. The majority (86%) of those who didn't have a feedback session believed that it would have been useful.

'Please comment on what CCAT could do differently'

Qualitative feedback indicated that many would have found this useful and for those who did get feedback, they reported that it was beneficial:

"It would have been useful to get feedback. There was not enough information afterwards. We did what we had to do but there was no follow-up of findings or recommendations. It is important for the foster carers to have access to recommendations because they are with the child 24/7." Participant 13B (Foster Carer)

"I didn't feel we got to hear the full outcome of the report after all those visits. I think it's a waste of money if we don't know what has been found in the reports." Participant 15B (Foster Carer)

"The social workers got feedback but the foster carer didn't. The child's day-to-day care could have been improved if there had been feedback given". Participant 49E (Foster Carer)

"It was good to get action points on her gait." Participant 51E (Foster Carer)

"If it hadn't been for the last bit of feedback I probably wouldn't have understood it as much as I did because I felt a bit left out during the assessment." Participant 14B (Foster Carer).

Parental Perspective

The number of parental respondents was low, and variability in quantitative responses was high (see Appendix 6). Parental qualitative responses to the statement '*Please comment on what CCAT could do differently*' are outlined below.

1. Team's facilitation of parents' understanding

Parents reported a lack of information and understanding, however one parent did feel that there had been the opportunity to ask questions throughout the assessment:

"[There was] little information beforehand, a bit more would have been helpful. We didn't know why we were going, we were just told to show up." Participant 44E (Father)

"They said if we didn't understand then we could ask for anything to be explained. They asked if we had any questions many times." Participant 44E (Father)

"I know I must not have understood the questions when I read the report. It wasn't my understanding of the questions." Participant 4A (Mother)

2. Parental satisfaction with Facilities and Appointment Schedule

One mother commented that her health needs had not been adequately accommodated in the schedule:

"There was no acknowledgement in the timetable of my workload and migraines." Participant 4A (Mother)

3. Impact of the assessment process on parents

Issues of culture and power difference were cited as factors affecting the impact of the assessment process on parents:

"They [CCAT] were not supportive... They let you know that they have more power because you are from a different country. They think that children are better off without their parents." Participant 19C (Mother)

"There were language barriers because I am not British. It put me at a disadvantage so that the social worker could win." Participant 4A (Mother)

4. Provision of feedback sessions to parents

Where a feedback session had been provided it was experienced as useful:

"It [the assessment] has helped us to sit down and talk.... We sat down with them [the team] after we had read the report, that was useful to understand the finding.... We learned some things about the girls that we didn't know before.... I think in the future we might be able to sit down and talk together differently." Participant 44E (Father).

Child Perspective

Only one child agreed to provide feedback (Appendix 6). They were largely satisfied with the assessment process and declined to provide qualitative feedback to the question '*What could CCAT do better?*'

Statistical Analyses

Statistical analyses were performed to see if difference existed between the responses of carers and family members (i.e. parents and the child). Results were non-significant, however some trends were identified. In general, carers were more likely to agree with statements that the team had listened to what they had to say (Mann-Whitney (14) $U = 11.0$, $p = .087$, *ns*). Carers were also more likely than family members to feel that they had gained something by going to the assessment, (Mann-Whitney (13) $U = 29$, $p = .170$, *ns*). Conversely, carers were also less likely to have felt that they had learnt something by coming to the assessment (Mann-Whitney (14) $U = 29$ $p = .370$, *ns*), and they more frequently reported that coming to assessment did not help them to think about things that happened (Mann-Whitney (14) $U = 26.5$, $p = .550$, *ns*). In a related chi-square analysis it was found that parents were more likely than carers to have received a feedback session ($\chi^2 [1, n = 12] = 0.17$, $p = .68$).

Foster Carers were significantly more likely than family members to feel that the team were supportive and respectful (Mann-Whitney [12] $U = 10.0$, $p = .04$; Mann-Whitney [12] $U = 6.0$, $p = .03$, respectively).

Presentation of Feedback

A presentation was provided to CCAT in September 2011, outlining the feedback collected from all respondents. The team responded to issues raised in the findings by discussing possible practice changes.

- CCAT typically provide basic feedback to foster carers about a child on the day of an assessment; particularly regarding risk issues and in line with good clinical practice. CCAT cannot disseminate other clinical and decision-related feedback of assessments to foster carers, however. The team created an information sheet for foster carers, which recognizes the difficult role that they play in the assessment process (Appendix 7).
- The team felt that they would be better able to tailor the day to a child's needs by contacting the foster carers prior to the assessment about their requirements and special considerations (e.g. the child's sleeping patterns or travel considerations).
- The team acknowledged that there was a shortfall regarding how the content of reports is fed back, due to the limitations of the legal process. A summary in the report of the child's needs could be provided for social workers and foster carers. The summary would be written in basic language, tailored to a child's level of understanding if it was to be shared with the child and would be shared with the family/ social worker after the report had filed and with permission of the court.
- The need to be upfront with children about the role of expert decision was highlighted in the team discussion.
- The suggestion of a closing letter to parents was proposed, to thank them for their co-operation and acknowledge that many parents find the process difficult and intrusive. The fact that the assessment process will often feel like an abnormal and artificial setting was cited as something to acknowledge.
- The development of a brochure was suggested to explain to parents why a contact assessment is being done and why it might be difficult.
- The idea of an introductory video was purposed, that could help inform families about CCAT. This would help circumvent any literacy difficulties that parents and children may have. This could be added to the team website and provide insight into what parents and children could expect in terms of who they will be meeting, and the layout of the rooms.
- The team discussed the benefits of having a network meeting to discuss the approach that other teams have taken to help inform families before the

assessment, and also to provide closure following the assessment process. This could help gain further insight into the ethical and philosophical issues faced by such services.

- As general protocol, the team proposed that they would also make sure to address with parents on the day of the assessment the intrusive nature of the assessment. This could serve to normalise parents' possible reactions.
- The team discussed the need to acknowledge issues of power and culture explicitly with families. Diversity and cultural competence was identified as a future training need for the team.
- It was also seen as important to address with the social worker, from the beginning, the potential for the assessment process to be distressing for families, and the need for support afterwards. This information could also be shared with the child's school, to enhance the systemic approach.

Discussion

Professional Feedback

In a climate where attention is being drawn to the heavy use of expert witness testimony, feedback indicates that CCAT adds value to the care proceedings process. Professionals reported high levels of satisfaction with the utility of the report and responsiveness of the team. They were largely satisfied with the time taken to respond to the initial enquiry and to carry out the assessment. This was in contrast to the findings of the Family Justice Review (Norgrove, 2011) that the use of other expert witness reports resulted in unnecessary delays for children. While recommendations provided by CCAT were acknowledged to be clear and concise, qualitative feedback expanded on concerns that recommendations may be unrealistic in the current economic climate. This finding has also been noted by Tucker and colleagues (2011), and is likely to be an ongoing concern for CCAT and other professionals when planning for the future of children involved in care proceedings.

It is useful to compare current findings with those outlined by Ireland (2012), who found expert witness psychology reports to be missing sections and demonstrate poor formatting. In contrast, all of the professionals in the current study agreed or strongly agreed that the presentation of the report was good. Overall, professionals gave largely positive feedback about the objectivity and sensitivity of the report. One fifth of the reports in the Ireland (2012) review were missing specific data, (e.g. psychometry), but still expressed opinions based on such data. All the current respondents agreed that CCAT had showed evidence for their views however. The majority of professionals in the current study felt that data was appropriately included: the psychometry made sense and it had been helpful to include verbatim interviews, but many respondents did not understand the implications of the psychometry. This indicates a need to better explain psychometric implications to a non-specialist audience. The majority of professional respondents thought that CCAT was sensitive to issues of culture and difference, but a significant minority neither agreed nor disagreed with this statement. This has been identified by the team as an area requiring follow-up and training. While only a minority of the reports reviewed by Ireland (2012) were categorised as 'good' or 'excellent', feedback received from professionals indicated that the CCAT reports considered in this study are likely to reach such standards.

The results indicate that overall professionals were satisfied with the quality of the service received from CCAT. Concerns about securing funding for the commissioning of reports is understandable, in light of the recent LSC reforms, and changes to the legal aid bill. Professionals were positive about the value of the MDT approach and half of the sample of professionals would instruct CCAT again. Results also show that professionals generally

believed that the report made a valuable contribution to the court's decision-making. These are positive reflections on the quality of the CCAT service. These commendations were also reflected in qualitative feedback that acknowledged the complexity of the work in relation to cost.

Foster Carer Feedback

The qualitative feedback provided by foster carers largely relates to practical rather than process issues, however feedback on the impact of the assessment did indicate that many foster carers reported that they had found the interviews too challenging and difficult. Although the interviews were challenging and difficult, almost all foster carers believed that the team had been respectful, supportive and had tried to reduce their anxiety. In many cases as the foster carers agreed that the team had thought about things that they were good at and had tried to understand them. This indicates that CCAT demonstrated balance and successfully used clinical skills to support foster carers during the assessment process.

The practical feedback from foster carers pertained to a perceived lack of information from the team about their findings. This was seen as impeding any day-to-day changes to the care of the child. In line with this feedback, the majority of foster carers did not feel that they would do things differently because of the assessment. Those respondents who had received feedback sessions from the team found it beneficial. The team responded to the feedback of foster carers concerning the appointments schedule by planning to change the structure of the day to better accommodate children's requirements.

Parental Feedback

Hunt (2010) notes that *"in the aftermath of care proceedings, whatever their outcome, parents are frequently in a state of emotional turmoil, struggling to come to terms with what has happened, and rebuild their lives"*. This is likely to have been a factor in the low parental response rate, and was specifically identified by one parent who declined to participate. In some cases the context of care proceedings was overwhelming for the parent, and it may have been too difficult for the parents to separate the expert witness assessment from the ultimate court ruling. The low representation of parents, in comparison to foster carers is a significant limitation to the generalisability of feedback to parents and children.

It may be unavoidable that undergoing an expert witness assessment is difficult, however the process has the potential to serve as a useful platform for parents to feel heard and have their views taken into account by an independent expert party. The opportunity to meet with clinicians who have skill and training in psychological assessment and treatment is provided, and this may help them to think about their own experience and how it impacts

on parenting roles. This benefit was specifically mentioned in qualitative feedback by a participating father.

Overall, qualitative feedback presented a mixed picture. Of note, parents were less likely than foster carers to feel that they had been listened to by the team. In particular, one mother (participant 4A) felt misunderstood. Parental concerns about words or behaviour being misinterpreted or taken out of context, and affecting the quality of evidence available to the court, has been reported elsewhere (Booth & Booth, 2004; 2005).

Parental feedback reflects similar findings by Freeman and Hunt (1998): parents wanted more information about what to expect during the assessment. This feedback can be addressed by the team through the development of an information sheet, a brochure for parents and the provision of appropriate feedback. If parents are better informed about the nature and purpose of the assessment, and receive suitable feedback this may also impact on what is learned through the assessment.

Both participating mothers highlighted issues of culture in their qualitative feedback. Brophy and colleagues (2005) previously noted that cultural differences may impact on parents' perception of the fairness of the assessment. Cultural differences may also influence parental satisfaction (Moorhead *et al.*, 2008). Cultural diversity and fairness have been acknowledged as issues that should be addressed both within the team and with the wider professional system.

Elsewhere in the literature ideas have been proposed to enhance the communication between expert professionals and families. For example, a network meeting was held at the outset of each case by one pilot expert witness team. This gave an opportunity for the parents and all the professionals involved to meet and to express their own perspective on the proceedings (Tucker *et al.*, 2011). Ongoing interaction between the team and parents throughout an assessment process has been found to be important for two reasons, firstly, it gives parents more information about changes they needed to make so that both they and the court can then see if change had been achieved; secondly, it avoids the situation where parents could feel ambushed, often just before a court hearing, by a negative view received from the expert (Tucker *et al.*, 2011).

The nature of the CCAT assessment is for a discrete purpose with a discrete timeframe. While CCAT are not providing a therapeutic intervention, the team has noted the importance of a consistent therapeutic relationship with clients, and they plan to ensure that this is emphasized as central to the assessment process in the future.

Child Feedback

Many children declined to participate, or had moved to placements where they could not be contacted. It may also be difficult for children to differentiate between the large numbers of professionals they have contact with during child-care proceedings. The individual child respondent reported high levels of satisfaction with the assessment process. In addition, qualitative feedback from foster carers provided additional information about the impact of the assessment process on children in their care. Ruegger (2001) has suggested that children need to be better prepared for the nature and purpose of expert witness assessments. Despite a dearth of results in the current study, the team has acknowledged an increased need to be upfront with children about the role of expert decision-making and the potential to provide feedback to children where appropriate.

Summary

This study forms the initial part of the audit cycle by providing a literature review, data collection and analysis, feeding back findings, and changing practice. It was a limitation of this study that such a re-evaluation was beyond the scope of the work. To complete the audit cycle future work should review the changes to practice and re-evaluate. In summary, CCAT provides high quality evidence to relevant professionals and an acceptable experience of assessment, however further scope for improvement was identified across practical and process issues. These results were fed back to the team and were used to instigate changes to practice.

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Appendices

Appendix 1: Contact Letters

South London and Maudsley 
NHS Foundation Trust

NATIONAL AND SPECIALIST CAMHS

Michael Rutter Centre for Children and Young People
The Maudsley Hospital
De Crespigny Park
Denmark Hill
London SE5 8AZ

Tel: 020-3228 3474

Fax: 020-3228 5011

Dear [Lead Solicitor]

Re: Case [name]

The Child Care Assessment Team is conducting an audit to evaluate the service we provide to professionals such as solicitors, social workers and guardians. We are also contacting the families and foster carers who have been seen as part of the assessment to gather their feedback of the service and process of assessment. We complete the audit after the report has been filed.

Our team is located in a teaching hospital and the audit is being conducted by staff that were not part of the clinical team that conducted the assessment. All data will be anonymised. The feedback is gathered after the report has been filed.

We do not want to add to your work load and our team will contact you to do a brief telephone interview (approx. 10 minutes). You will not be asked to do anything in addition. We will also contact the family, other professionals involved in the case. We have enclosed a copy of each of the questionnaires (one for professionals, one for family members) for your information. Unless we hear otherwise, we will assume consent for this audit.

Many thanks in anticipation of your help with this audit.

Yours sincerely

Claire Tobin
Clinical Psychologist in training
On behalf of the Child Care Assessment Team.

Encl. A copy of the letter to families
Copy of questionnaire for professionals
Copy of questionnaire to families/ carers

NATIONAL AND SPECIALIST CAMHS

Michael Rutter Centre for Children and Young People

The Maudsley Hospital

De Crespigny Park

Denmark Hill

London SE5 8AZ

Tel: 020-3228 3474

Fax: 020-3228 5011

Dear family members/ carers,

We are writing to you because you completed an assessment with the Child Care Assessment Team based at the Maudsley Hospital. We would like to ask you some questions about your experience of doing the assessment with our team. This feedback helps us to improve the experience for other families and young people.

Our team is part of a teaching hospital and the feedback is being completed by staff that were not part of the clinical team who you meet. All answers you give will be anonymous.

We will contact you after the report has been filed. We do not want to take up lots of your time. Our team will contact you to do a brief telephone interview (approx. 10 minutes). You will not be asked to do anything else. If you do not wish to be contacted as part of this audit, please let us know. You can always let the person who calls you know on the phone.

Many thanks in anticipation of your help with this feedback.

Yours sincerely

Claire Tobin

Clinical Psychologist in training

On behalf of the Child Care Assessment Team

Appendix 2: Professionals' Interview

1. Please state your involvement with the case

<input type="checkbox"/> Lead Solicitor	<input type="checkbox"/> Barrister
<input type="checkbox"/> Other Solicitor	<input type="checkbox"/> Other (please specify):
<input type="checkbox"/> Guardian	

2. How did you come to hear about the Team?

<input type="checkbox"/> Have used the team before	<input type="checkbox"/> Saw leaflet
<input type="checkbox"/> Recommended by a colleague	<input type="checkbox"/> Saw website
<input type="checkbox"/> Online search	<input type="checkbox"/> Other (please specify):

3. Utility of Report: To what extent do you agree that?

	Strongly Agree	Agree	Average	Disagree	Strongly Disagree
The recommendations made in the report were clear and concise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The report made a valuable contribution to the Court's decision making	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The report made a valuable contribution to your own report writing in relation to this case (applicable to guardian)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please comment on what CCAT could do differently:

4. Satisfaction and Responsiveness: How satisfied were you with the following?

	Very satisfied	Satisfied	Average	Dissatisfied	Very dissatisfied
The time it took for the team to respond to your initial enquiry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information you had about the team's services prior to them being appointed by the Court	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Communication with CCAT during the referral stage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The time taken for the team to carry out their assessment from the date of the referral	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The time taken for the report to be filed following assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please comment on what CCAT could do differently:

5. Structure of the report: Please rate your agreement with the following statements:

	Strongly Agree	Agree	Average	Disagree	Strongly Disagree
The report was too long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It was helpful to include verbatim accounts of the interviews in the appendices	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The presentation of the report was good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CCAT showed the evidence for the views made	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It was clear how CCAT reached its conclusions? (i.e. did they show their 'working out')	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The psychometry made sense	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understood the practical implications of the psychometry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prompt: what could CCAT do differently?					

Please comment on what CCAT could do differently:

6. Objectiveness of Report: Please rate your agreement with the following statements about the CCAT report:

	Strongly Agree	Agree	Average	Disagree	Strongly Disagree
The report was objective	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The report was written sensitively	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The report reduced the disputes between the parties					
The report reduced the length of the time required in court					
The report was sensitive to issues of culture and diversity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please comment on what CCAT could do differently:

Did your client understand the outcome of the report?

7. Client Benefits: Did your client agree with the outcome of the report?

<input type="checkbox"/> Yes	<input type="checkbox"/> Partially Disagreed
<input type="checkbox"/> No	<input type="checkbox"/> Partially Agreed

8. Funding for CCAT: Please rate your agreement with the following statements:

	Strongly Agree	Agree	Average	Disagree	Strongly Disagree
It was difficult to secure the funding from the LSC for CCAT assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Why/ Can you tell us more?					
We would instruct CCAT again based on the quality of the report in relation to the fee charged	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Why/ not? E.g. did you think the report was good but too expensive, quality not good too expensive					
CCAT rates were competitive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please comment on what CCAT could do differently

Appendix 3: Foster Carers', Parents' and Children's Interview

Please rate your agreement with the following statements:

	Strongly Agree	Agree	Average	Disagree	Strongly Disagree
After the first meeting with CCAT, I had enough information about the assessment process	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understood why the assessment was being done	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understood the questions that were asked during the assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was given an opportunity to ask questions to the team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please comment on what CCAT could do differently

Please rate your satisfaction with the facilities:

	Yes	No
Did we provide you enough toys?	<input type="checkbox"/>	<input type="checkbox"/>
Did you need an interpreter?	<input type="checkbox"/>	<input type="checkbox"/>
Did we provide an interpreter?	<input type="checkbox"/>	<input type="checkbox"/>
Do you have a physical disability?	<input type="checkbox"/>	<input type="checkbox"/>
Did we cater for any disability?	<input type="checkbox"/>	<input type="checkbox"/>

Please comment on what CCAT could do differently

Please rate your satisfaction with the appointment schedule

	Strongly Agree	Agree	Average	Disagree	Strongly Disagree
I was given the plan of appointments in plenty of time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If the team changed the plan of appointments, they gave me enough notice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please rate your agreement with the following statements:

	Strongly Agree	Agree	Average	Disagree	Strongly Disagree
The team tried hard to understand me and my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The team helped me feel less anxious/worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The assessment helped me to think about things that have happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't feel I gained anything from coming here	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The interviews were too challenging and difficult	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The interviews were challenging and difficult but that was ok	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I have learnt something from the assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I will do things differently because of this assessment					
The team listened to what I had to say	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The team were supportive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The team were respectful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The team thought about things that I am good at	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The team thought about how I might have a positive role in my child(ren)'s life in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please comment on what CCAT could do differently					

8. Did you have a feedback session with the team about the findings of the assessment?

☐ Yes

☐ No

Please rate your satisfaction with feedback:

	Strongly Agree	Agree	Average	Disagree	Strongly Disagree
If yes: I found the feedback session with the team useful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If no: I did not have a feedback session but would have found it useful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please comment on what CCAT could do differently

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Appendix 4: Descriptive Statistics for Professional Responses

Table 1: Professional's satisfaction with the CCAT's service

Interview items	Responses									
	Very satisfied/ Strongly agree		Satisfied / Agree		Average/Neither Agree nor Disagree		Dissatisfied/ Disagree		Very dissatisfied/ Strongly disagree	
	n	%	n	%	n	%	n	%	n	%
Utility of the report										
1. Clear and concise recommendations	7	46.7	5	33.3	2	13.3	1	6.7	0	0
2. Report made a valuable contribution to the court's decision-making (n=15)	7	46.7	5	33.3	2	13.3	1	6.7	0	0
3. Report made valuable contribution to your own report writing (n=10)	5	50.0	3	30.0	2	20.0	0	0	0	0
Responsiveness of the team										
4. Time it took for the team to respond to your initial enquiry (n=14)	6	42.9	6	42.9	2	14.3	0	0	0	0
5. The information you had about the Team's services prior to them being appointed by the court (n=14)	2	14.3	8	57.1	2	14.3	1	7.2	1	7.2
6. Communication with CCAT during the referral stage (n=14)	5	35.7	9	64.3	0	0	0	0	0	0
7. The time taken for the team to carry out their assessment from the date of the referral (n=14)	5	35.7	6	42.9	3	21.4	0	0	0	0
8. The time taken for the report to be filed following the assessment (n=14)	4	28.6	6	42.9	2	14.3	2	14.3	0	0

Interview items	Responses									
	Very satisfied/ Strongly agree		Satisfied / Agree		Average/Neither Agree nor Disagree		Dissatisfied/ Disagree		Very dissatisfied/ Strongly disagree	
	n	%	n	%	n	%	n	%	n	%
Structure										
9. Report too long (<i>n</i> =15)	4	26.7	4	26.7	1	6.7	6	40.0	0	0
10. It was helpful to include verbatim accounts of the interviews in the appendices (<i>n</i> =15)	6	40.0	6	40.0	1	6.7	2	13.3	0	0
11. The presentation of the report was good (<i>n</i> =15)	5	33.3	10	66.7	0	0	0	0	0	0
12. CCAT showed evidence for views made (<i>n</i> =15)	4	26.7	11	73.3	0	0	0	0	0	0
13. It was clear how CCAT had reached their conclusions (<i>n</i> =6)	1	16.7	5	83.3	0	0	0		0	0
14. The psychometry made sense (<i>n</i> =14)	3	21.4	6	42.9	3	21.4	1	7.1	1	7.1
15. I understood the practical implications of the psychometry (<i>n</i> =5)	0	0	3	60.0	1	20.0	1	20.0	0	0

Interview items	Responses									
	Very satisfied/ Strongly agree		Satisfied / Agree		Average/Neither Agree nor Disagree		Dissatisfied/ Disagree		Very dissatisfied/ Strongly disagree	
	n	%	n	%	n	%	n	%	n	%
Objectiveness										
16. The report was objective (n=15)	5	33.3	9	60.0	1	6.7	0	0	0	0
17. The report was written sensitively (n=15)	5	33.3	7	46.7	2	13.3	1	6.7	0	0
18. The report reduced disputes between parties (n=6)	2	33.3	1	16.7	1	16.7	2	33.3	0	0
19. The report reduced the amount of time required in court (n=6)	2	33.3	1	16.7	1	16.7	2	33.3	0	0
20. The report was sensitive to issues of culture and diversity (n=15)	6	40.0	4	26.7	5	33.3	0	0	0	0
Client benefits										
21. Did your client understand the outcome of the report? (n=6)	6	Yes 100	0	No 0						
22. Did your client agree with the outcome of the report? (n=14)	1	Yes 7.1	7	No 50.0	2	Partially agreed 14.3	4	Partially disagreed 28.6		

Interview items	Responses									
	Very satisfied/ Strongly agree		Satisfied / Agree		Average/Neither Agree nor Disagree		Dissatisfied/ Disagree		Very dissatisfied/ Strongly disagree	
	n	%	n	%	n	%	n	%	n	%
Funding										
23. It was difficult to secure funding from the LSC for the CCAT assessment (n=12)	6	42.9	2	14.3	2	14.3	2	14.3	0	0
25. We would instruct CCAT again based on the quality of the report in relation to the fee charged (n=14)	3	21.4	4	28.6	5	35.7	2	14.3	0	0
26. CCAT rates were competitive (n=5)	0	0	3	60.0	1	20.0	1	20.0	0	0

Appendix 5: Descriptive Statistics for Foster Carer Responses

Table 2: Foster Carer satisfaction with the CCAT's service

Interview items	Responses									
	Very satisfied/ Strongly agree		Satisfied / Agree		Average/ Neither Agree nor Disagree		Dissatisfied/ Disagree		Very dissatisfied/ Strongly disagree	
	n	%	n	%	n	%	n	%	n	%
Facilitation of client's understanding										
1. After the first meeting I had enough information about the assessment process (<i>n</i> =10)	0	0	8	80.0	0	0	0	0	2	20.0
2. I understood why the assessment was being done (<i>n</i> =10)	3	30.0	5	50.0	1	10.0	0	0	1	10.0
3. I understood the questions that were asked during the assessment (<i>n</i> =10)	6	60.0	4	40.0	0	0	0	0	0	0
4. I was given the opportunity to ask questions to the team (<i>n</i> =10)	6	60.0	2	20.0	0	0	2	20.0	0	0
Satisfaction with Facilities and Appointment Schedule										
	Yes				No					
	n		%		n		%			
5. Enough toys?	5		50.0		5		50.0			
6. Interpreter needed?	0		0		10		100			
7. Interpreter Provided?	0		0		10		100			
8. Physical disability?	1		10.0		9		90.0			
9. Physical disability catered for?	1		10.0		9		90.0			

Interview items	Responses									
	Very satisfied/ Strongly agree		Satisfied / Agree		Average/ Neither Agree nor Disagree		Dissatisfied/ Disagree		Very dissatisfied/ Strongly disagree	
	n	%	n	%	n	%	n	%	n	%
10. Given the plan of appointments in plenty of time? (n=10)	4	40.0	3	30.0	1	10.0	2	20.0	0	0
11. Enough notice of changes? (n=9)	4	44.4	4	44.4	0	0	0	0	1	11.1
Impact of the assessment process										
12. Team tried hard to understand me and my family (n=10)	3	30.0	6	60.0	1	10.0	0	0	0	0
13. Team helped me feel less anxious/ worried (n=9)	2	22.2	6	66.7	1	11.1	0	0	0	0
14. Assessment helped me think about things that have happened (n=10)	2	20.0	5	50.0	1	10.0	1	10.0	1	10.0
15. I don't feel I gained anything from coming here (n=9)	1	11.1	3	33.3	0	0	3	33.3	2	22.2
16. The interviews were too challenging and difficult (n=10)	2	20.0	5	50.0	1	10.0	1	10.0	1	10.0
17. The interviews were challenging and difficult but that was OK (n=9)	1	11.1	3	33.3	0	0	3	33.3	2	22.2
18. I have learnt something from the assessment (n=10)	2	20.0	3	30.0	1	10.0	2	20.0	2	20.0

Interview items	Responses									
	Very satisfied/ Strongly agree		Satisfied / Agree		Average/ Neither Agree nor Disagree		Dissatisfied/ Disagree		Very dissatisfied/ Strongly disagree	
	n	%	n	%	n	%	n	%	n	%
19. I will do things differently because of the assessment (<i>n</i> =7)	1	14.3	1	14.3	1	14.3	2	28.6	2	28.6
20. The team listened to what I had to say (<i>n</i> =10)	3	30.0	6	60.0	1	10.0	0	0	0	0
21. The team were supportive (<i>n</i> =10)	4	40.0	6	60.0	0	0	0	0	0	0
22. The team were respectful (<i>n</i> =8)	4	50.0	4	50.0	0	0	0	0	0	0
23. The team thought about things that I am good at (<i>n</i> =7)	0	0	5	71.4	0	0	1	14.3	0	0
24. The team thought about how I might have a positive role in my child(ren)'s future (<i>n</i> =7)	2	28.6	4	57.1	0	0	0	0	1	14.3

Provision of feedback sessions

Three participants (30%) reported having had a feedback session with the team about the findings of the assessment; seven (70%) did not have such a session.

25. If a feedback session was provided (<i>n</i> =3): I found the feedback session with the team useful.	2	66.6	0	0	0	0	0	0	1	33.3
26. If no feedback session was provided (<i>n</i> =7): I did not have a feedback session, but would have found it useful.	3	43.0	3	42.9	0	0	0	0	1	14.3

Appendix 6: Descriptive Statistics for Parent and Child Responses

Table 3: Parental and Child satisfaction with the CCAT's service

Interview items	Responses			
	Mother 1	Mother 2	Father 1	Child
Team's facilitation of understanding				
1. After the first meeting I had enough information about the assessment process	<i>Disagree</i>	<i>Disagree</i>	<i>Disagree</i>	<i>Agree</i>
2. I understood why the assessment was being done	<i>Strongly Disagree</i>	<i>Disagree</i>	<i>Disagree</i>	<i>Agree</i>
3. I understood the questions that were asked during the assessment	<i>Disagree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Agree</i>
4. I was given the opportunity to ask questions to the team	<i>Strongly Disagree</i>	<i>Strongly Disagree</i>	<i>Agree</i>	<i>Agree</i>
5. Enough toys?	<i>No</i>	<i>No</i>	<i>Yes</i>	<i>Yes</i>
6. Interpreter provided where needed?	<i>Not needed</i>	<i>Not needed</i>	<i>Not needed</i>	<i>Not needed</i>
7. Physical disability catered for?	<i>Yes</i>	<i>Not needed</i>	<i>Not needed</i>	<i>Not needed</i>

Interview items	Responses			
	Mother 1	Mother 2	Father 1	Child
8. Given the plan of appointments in plenty of time?	<i>Disagree</i>	<i>Neither Agree nor Disagree</i>	<i>Strongly Agree</i>	<i>Agree</i>
9. Enough notice of changes?	<i>Neither Agree nor Disagree</i>	<i>Neither Agree nor Disagree</i>	<i>Agree</i>	<i>Agree</i>
10. Team tried hard to understand me and my family	<i>Disagree</i>	<i>Strongly Disagree</i>	<i>Agree</i>	<i>Agree</i>
11. Team helped me feel less anxious/ worried	<i>Agree</i>	<i>Disagree</i>	<i>Disagree</i>	<i>Neither Agree nor Disagree</i>
12. Assessment helped me think about things that have happened	<i>Agree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Agree</i>
13. I don't feel I gained anything from coming here	<i>Disagree</i>	<i>Strongly Agree</i>	<i>Agree</i>	<i>Agree</i>
14. The interviews were too challenging and difficult	<i>Agree</i>	<i>Neither Agree nor Disagree</i>	<i>Disagree</i>	<i>Strongly Agree</i>
15. The interviews were challenging and difficult but that was OK	<i>Disagree</i>	<i>Disagree</i>	<i>Neither Agree nor Disagree</i>	<i>Strongly Agree</i>
16. I have learnt something from the assessment	<i>Agree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Neither Agree nor Disagree</i>

Interview items	Responses			
	Mother 1	Mother 2	Father 1	Child
17. I will do things differently because of the assessment	<i>Strongly Disagree</i>	<i>Strongly Disagree</i>	<i>Agree</i>	<i>Disagree</i>
18. The team listened to what I had to say	<i>Neither Agree nor Disagree</i>	<i>Strongly Disagree</i>	<i>Agree</i>	<i>Agree</i>
19. The team were supportive	<i>Agree</i>	<i>Strongly Disagree</i>	<i>Agree</i>	<i>Agree</i>
20. The team were respectful	<i>Agree</i>	<i>Strongly Disagree</i>	<i>Agree</i>	<i>Agree</i>
21. The team thought about things that I am good at	<i>Neither Agree nor Disagree</i>	<i>Strongly Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
22. The team thought about how I might have a positive role in my child(ren)'s future	<i>Disagree</i>	<i>Strongly Disagree</i>	<i>Agree</i>	<i>Not applicable</i>
<p>Mother 1 and father 1 had a feedback session with the team about the findings of the assessment The child participant did not. Mother 2 was unsure if she had feedback with the team.</p>				
23. If a feedback session was provided, did you find it useful?	No		Yes	
24. If no feedback session was provided would you have liked one?				Yes

Appendix 7: Information sheet for Foster Carers

